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Category 1: Case Ascertainment - Innovative Approaches, Use of Physician Office Data, Prenatal Surveillance, Pediatric Cardiac Registries, Record Linkage

C1.1 Alaska Birth Defects Registry

Increased Risk of Hirschsprung's Disease Among Alaska Natives Identified Following Verification of Reported Cases, 1996-2006

K. Janine Schoellhorn, Sandra Collins

Background: Hirschsprung's disease (HD), or congenital megacolon may result in intestinal obstruction and chronic constipation, abdominal distention and inability to pass fecal matter. During birth years 1996-2002, reported HD birth prevalence in Alaska was 13.3 per 10,000 live births, approximately six times higher than national estimates, with no significant disparities by race, maternal age, Alaska Native status or maternal residence. Two case verification sample surveys, initiated at major hospitals in 2002 and 2004, reported high positive predictive value for reports of HD to the Alaska Birth Defects Registry (ABDR), lending support to the validity of elevated HD prevalence estimates. Because of the high reported prevalence occurring throughout all Alaskan populations, we developed plans to evaluate genetic and environmental HD risk factors. As preparatory work, we a complete case verification study of reported HD in 2008.

Methods: The ABDR is a statewide population-based birth defects registry utilizing passive surveillance and multiple source reporting methodology. ABDR staff traveled to hospitals and clinics to review medical records for all children identified with HD with birth years 1996-2008. HD was confirmed when a child's medical chart documented positive diagnostic testing by contrast x-ray (barium enema) or rectal biopsy. Reported HD was ruled out when the chart indicated that diagnostic tests were negative, when there was a physician note that HD had been ruled out, or when an alternate diagnosis was confirmed. Inconclusive findings occurred when the medical chart lacked information confirming or ruling out HD.

Results: During birth years 1996-2006 HD prevalence fell from 10.5 per 10,000 live births before case verification to 2.8 per 10,000 live births after case verification. HD prevalence following case verification was 50% lower than previous estimates among Alaska Native infants (5.3 compared to 10.8 per 10,000 live births) and 81% lower among non-Native infants (1.8 compared to 9.9 per 10,000 live births). Following case verification, Alaska Native infants had confirmed HD rates three times that of non-Native infants (Relative Prevalence (RP) = 3.2, 95% CI: 1.6 - 6.5). Predictive value positive for a report of HD to the ABDR varied by reporting source and was highest for Alaska's two largest hospitals and lowest for reports received through Medicaid.

Conclusions: A case-verification study in Alaska demonstrated that Alaska does not have an increased risk of HD overall but that the Alaska Native population has a three-fold increase in risk compared to the non-Native population. These findings have important implications for development of etiologic hypotheses yet were not apparent during evaluation of pre-verification reports.

C1.2 California Birth Defects Monitoring Program

Analysis of Missed Cases of Neural Tube Defect and Abdominal Wall Defect Using the Two-Source Capture-Recapture Approach

Kate Cordell, Nuny Cabanting, Marcia Ehinger

Objective and Background: The California Birth Defects Monitoring Program (CBDMP) utilizes active ascertainment techniques to review medical records of over 40% (n=225,000) of annual births in California. The California Office of Statewide Health Planning and Development (OSHPD) provides public datasets, which consist of records for each inpatient discharged from hospitals statewide. This study linked the data sources of the Linked Patient Discharge Data (PDD) to the CBDMP Registry via the Vital Statistics Birth Cohort file of live births.

The objective of this project was to determine the characteristics of cases identified by one source but not the other. It is the intent that this information would be used to determine limitations, improve ascertainment methods and estimate the completeness of each source. The birth conditions of anencephaly, spina bifida and abdominal wall defect (AWD) (gastroschisis or omphalocele) were chosen for analysis in this study as conditions with accurate diagnoses that are evident at birth.

Methods: PDD and CBDMP registry cases were linked to Vital Statistics Birth Cohort records for the counties available in the birth defects registry between 2000 – 2005 (n=755,166 live births). Counts identified live-born cases of the selected conditions captured by both data sources, CBDMP only or PDD only. A decision tree was used to profile valid cases, and exclusion criteria removed likely miscoded, mismatched, and missing data records. A total of 9.7% (n=81/836) of cases had potential data quality issues. Mismatches between sources were corrected by hand matching where possible (n=28/836, 3.4%). A total of 90% (n=73/81) anencephaly, 96% (n=243/253) spina bifida and 93% (n=469/502) AWD cases were validated for further analysis. For each data source (CBDMP or PDD), recursive partitioning of present versus absent cases was performed to detect associated characteristics and potential interactions, from which a final multivariate logistic regression model was created. Limitations of this study include the potential for misdiagnosis and reliance on probabilistic linkages.

Results: CBDMP identified 83.6% (n=61/73) and PDD identified 84.9% (n=62/73) of the total cases of anencephaly. CBDMP identified 92.2% (n=224/243) and PDD identified 77.4% (n=188/243) of the total cases of spina bifida. CBDMP identified 85.1% (n=399/469) and PDD identified 91.7% (n=430/469) of the total cases of AWD.

Cases of anencephaly with very low birth weight (BW) had an increased odds of being absent from CBDMP records (BW<750g: OR=33.0, 95%CI 5.3-200.0; BW 750-1500g: OR=7.8, 95% CI 1.1-52.6) as compared to cases of birth weight greater than 1500g. Cases of spina bifida and AWD with routine discharges had an increased odds of being absent from CBDMP records (spina bifida: OR=7.0 (95%CI 2.2 – 22.0; AWD: OR=6.4, 95%CI 3.0 – 13.3) as compared to cases that were transferred or died, after adjusting for the identification of appropriate surgical procedures.

For PDD records, there were no significant characteristics that were associated with the absence of anencephaly records, although there was a trend (p=0.06) toward the absence of cases with multiple (>3) versus few diagnosed conditions. Cases of spina bifida and AWD that were discharged after less than one week had an increased odds of being absent from PDD records (spina bifida: OR=3.3 (95%CI 1.5 – 7.3; AWD: OR=3.2, 95%CI 1.0 – 10.2) as compared to cases that were transferred or died within the first week, after adjusting for the identification of appropriate surgical procedures. Cases of spina bifida and AWD that

died or were transferred within the first week trended toward an increased odds of being absent from PDD records (spina bifida: OR=2.2 (95%CI 0.8 – 5.6; AWD: OR=2.7, 95%CI 1.1 – 6.6) as compared to cases with birth hospital stays of more than a week, after adjusting for the identification of appropriate surgical procedures.

Conclusions: The use of two data sources allowed for the modeling of valid case profiles based on cases captured by both data sources. CBDMP was more likely to identify cases involving transfers or death as compared to those with routine discharges for the conditions of spina bifida and AWD. For anencephaly, CBDMP was less likely to identify cases born with a birth weight of less than 1500g. Many of these cases were later found as records in CBDMP registry that were not linked to birth certificates, because the cases were coded as therapeutic abortions. The identification of cases by PDD was significantly associated with the disposition of the infant (still in hospital, discharged or died/transferred) at one week after birth.

Capture-recapture methods estimate that using both PDD and CBDMP together allows for the identification of 97.8% of all cases of anencephaly, spina bifida, gastroschisis, and omphalocele. Future investigation will use the patient profiles identified in this study to evaluate the causes for discordance between identified cases in PDD and CBDMP.

C1.3 Department of Defense Birth and Infant Health Registry

Ensuring the Quality of Infant Health Data: Why a Simple Data Pull Will Not Work

Sevick CJ, Conlin AS, Gumbs GR, Smith TC

Objective: The DoD Birth and Infant Health Registry captures comprehensive healthcare data to define live births and infant health outcomes among children born to military families. These data are used to evaluate the impact military occupational exposures may have on reproductive health. Data quality is of paramount importance for accurately assessing reproductive health outcomes.

Methods: For over a decade, the Registry Team has adapted to constantly evolving military electronic data, developing methods and complex algorithms for rigorous cleaning of infant health data. Objectives include identifying liveborn infants; accounting for multiple births; assigning birth outcomes; and linking infants to parental demographic, occupational, and exposure data.

Results: Over 800,000 infants were born to military families between 1998 and 2006. Prevalence and types of birth defects are consistent with the general population. Validation efforts reveal strong agreement between the electronic data and individual medical records.

Conclusions: Complex data linking and cleaning algorithms have allowed the Registry to provide accurate counts of live births and reduce misclassification bias. The Registry Team continues to refine these methods to enhance the monitoring of reproductive health among military families.

C1.4 Korean Center for Research Environmental Disease – Birth Defects (CRED-BD)

Physician-Active Birth Defects Surveillance Program in Korea

Jong Kwan Jun, Hea Jin Park, Kiyong Lee, Yun-Chul Hong, Soo-Hun Cho

Objective: Birth defects surveillance is widely accepted and operated for promoting public health in many countries. We reviewed many programs and found they spent lot of resources to search cases of birth defects. Physician has a key role in diagnosis and management of birth defects. If they notify it to the surveillance center whenever he or she find a case of birth defects, tedious and time-consuming activity of record review can be avoided. Although physicians may take a charge of the program, they are usually excluded in initial data collection in most programs. Korea has about 47 millions of population and prenatal diagnosis is done very actively. For example, most Korean pregnant women received average 6 to 10 ultrasonographic examinations during pregnancy. Many experts are available for targeted ultrasonography including fetal echocardiography. However, no real surveillance program started until three-year birth defects surveillance program supported by Korean Ministry of Environment was launched for research purpose from July 2008.

Methods: This program consists of three parts which are clinical investigation team, information management team and environmental factor analysis team. Eight hospitals participated in this program and their number of annual delivery encompasses about 20,000. Excluding 3,000 deliveries in one tertiary and two secondary hospitals, the other 17,000 deliveries come from 5 primary hospitals. Ten obstetricians, eight pediatricians, four epidemiologists, three environmental specialists and 10 researchers are involved. Role of clinical investigation team is to recruit pregnant women. Basic information of pregnant women and delivery, questionnaire and blood and urine samples are collected from all pregnant women.

Results: If birth defects are suspected in a fetus or a baby, it is directly reported to clinical investigation team by researcher who works with clinician in the hospital and the fetus or baby are tracked as tentative active cases until they are determined as having birth defects or being normal. We have two types of questionnaire. Type A questionnaire is short and simple. We get it from all pregnant women. Type B questionnaire is more comprehensive and is received from pregnant women who visit secondary and tertiary hospitals. Environmental factor analysis team measures volatile organic carbons (VOC). Pregnant women take the kit home and place it on the TV for 4 days and return it to the environmental factor analysis team by quick delivery service. Information management team arranges, collects and analyzes all these data.

Conclusions: This system looks passive. But it is a physician-active system in the point that a responsible physician is actively involved in case recruitment. Main problem is how to maintain physicians active. Members of this program were interested in birth defects surveillance and gathered by their own will. However, if it is intended to be a nation-wide surveillance program, incentive for physicians may be needed.

C1.5 Michigan Birth Defects Program

The Prenatal Ascertainment Project: Birth Outcomes for Fetuses Diagnosed with Defects Prenatally in Michigan

Mary Kleyn, Steven Korzeniewski, Joan Ehrhardt, Violanda Grigorescu

Objective: The Michigan Birth Defects Program encompasses the Michigan Birth Defects Registry (MBDR) and Follow-up Program. A statewide, passive surveillance system, the MBDR currently does not include information on birth defects identified in pregnancies ending in spontaneous abortion before 20 weeks of gestation or elective termination. The Prenatal Ascertainment Project is a study intended to assess the birth outcomes for pregnancies affected by a prenatally diagnosed birth defect.

Methods: From January 2001 through December 2007, eight hospitals voluntarily provided case reports for birth defects identified prenatally; the reports included information on diagnoses, maternal demographics, and pregnancy outcome. The eight participating hospitals were located in southeastern, central, and western Michigan.

Results: Throughout the duration of the study, case reports were received for 1,492 fetuses with prenatally diagnosed birth defects. Of the 1,492 fetuses, 68% (N=1006) were diagnosed with only one birth defect. About one in five [19% (N=282)] had 2 birth defects and 16% (N=202) were diagnosed with 3 or more. The diagnoses of birth defects were missing for two cases while 66 did not have a recorded gestational age at time of diagnoses. Nearly 80% (N=1140) of 1,426 fetuses with known gestational age were diagnosed prior to 23 completed weeks of gestation, the latest gestational age for legal termination in Michigan. A known birth outcome was reported for 854 (57%) fetuses. Of these, approximately 40% (N=346) were live born, 48% (N=407) were terminated, 8% (N=69) were stillborn, and 4% (N=32) were miscarried. Termination was the most common outcome for fetuses diagnosed with a defect before 20 weeks gestation and for fetuses with defects of the nervous system or chromosomal anomalies.

Conclusions: The data collected by the Prenatal Ascertainment Project is not representative of all birth defects identified prenatally in Michigan. However, the findings enhanced the knowledge about birth outcomes for fetuses with defects and how birth outcomes may affect the overall rate of birth defects. This study led us also to believe that specific birth defect diagnostic groups (nervous system defects and chromosomal anomalies) may be underestimated considering the current reporting is only for live born and stillborn infants. Collecting data on fetuses with birth defects that are miscarried prior to 20 weeks gestation or terminated would provide more accurate estimates of birth defects rates.

C1.6 National Center on Birth Defects and Developmental Disabilities, CDC

Congenital Heart Defects and Associated Anomalies in Atlanta

A Miller, T Riehle-Colarusso, C.J. Alverson, JL Frías, C Siffel, A Correa

Objective: Few population-based epidemiological data are available on the frequency of associated anomalies in children with congenital heart defects (CHD). The aim of our study was to identify preferential positive and negative associations between CHD and non-cardiac associated anomalies.

Methods: All records of infants with CDC/BPA codes for cardiac defects (745.000 – 747.900) in the Metropolitan Atlanta Congenital Defects Program (MACDP) were reviewed and heart defects of those without chromosomal or single-gene disorders were classified according to a standard clinical nomenclature system adapted from the Society of Thoracic Surgeons. Frequencies of associated non-cardiac anomalies were obtained, and univariate logistic regression analyses were conducted to identify significant associations ($p < 0.05$).

Results: Among 39,600 live- and stillborn infants born between 1968 and 2003 we identified 6,229 with CHD, excluding those with chromosomal abnormalities or single-gene determined syndromes. Among them 1,307 (21 %) had additional major non-cardiac anomalies. The frequency of these anomalies varied, as follows, for different types of heart defects: atrioventricular septal defects (AVSD) (29%), atrial septal defects (24%), conotruncal (22%), left or right ventricular outflow tract obstruction (20%, 18%, respectively), cardiac looping (17%), and ventricular septal defects (16%). Preferential positive associations (crude odds ratio [OR] > 1.0) between CHD and non-cardiac malformations included spleen anomalies (OR = 4.85; 95% confidence interval [CI]: 3.2 – 7.4), esophageal (OR = 1.7; 95% CI: 1.2-2.6) and duodenal (OR = 2.4; 95% CI: 1.5-4.0) atresia/stenosis. Preferential negative associations (OR < 1.0) included neural tube defects (OR = 0.2; 95% CI: 0.1-0.2), and congenital hip dysplasia (OR = 0.3; 95% CI: 0.2-0.5).

Conclusions: Among infants with CHD and no identified chromosomal abnormality or single-gene determined syndrome, 21% had another major non-cardiac malformation. AVSD, atrial septal defects, and outflow tract obstruction defects had the highest frequencies of associated major anomalies. Thus, infants with CHD warrant careful examination for the presence of non-cardiac anomalies. Similarly, the presence of CHD should be thoroughly investigated in children presenting with certain non-cardiac anomalies. Further clinical review and analysis is needed to determine whether these additional defects have a presumed common pathogenetic mechanism or are unrelated to the CHD.

C1.7 Nebraska Department of Health and Human Services, Division of Public Health, Community Health Section

Passive Data Collection Aided by Active Multiple Data Linkages: Sensitivity Analysis by Race and Geography

Ming Qu, Julie Miller, Carla Becker, Norm Nelson, Ge Lin

Background: Nebraska has used a passive birth defect reporting system for more than 30 years. With an increased and wider availability of electronic records, the Nebraska Birth Defect Registry (NBDR) has been actively linking various other health data systems for verifying case findings and assessing differences in potential outcomes in the data reporting process and research finding.

Method: Data from the last 20 years of the Nebraska Birth Defect Registry have been classified according to the availability of other paper and electronic records by birthing hospitals, reporting facility, and mother's residence. Statistical trends were established and evaluated for missing data "hot spot", where potential birth defects were either deemed under reporting, or potential birth defect spikes occurred. Using the multiple data linkage system, an indicator is signaled the likelihood of under reporting versus defect spiking.

Result: It was found that most under reporting from birthing hospitals could be partially recovered from the multiple linkage system. The combination of geographic and reporting facility scan for potential case inconsistencies provides the best clue on potential missing or spiking cases.

Conclusion: Research and reporting results could be substantially different without the assistance of active multiple data linkages. Even though a resource poor state may not be able to afford an active birth defect registry, some active case finding techniques should be use to maximize the case finding effort.

C1.8 New York State Congenital Malformations Registry

Development of a Web-based System for Case Reporting, Data Management and Communication for the Birth Defects Registry in New York State

Philip K. Cross, Ying Wang, Patricia M. Steen, Charlotte M. Druschel, Jennifer L. Cukrovany, Zhen Tao, David R. Marion

Background: The Congenital Malformations Registry (CMR) of the New York State Department of Health (NYSDOH) is one of the largest statewide, population-based birth defects registries in the nation. Annually, the CMR receives reports on more than 10,000 children who are born or reside in New York State and are diagnosed before the age of two years with a major congenital anomaly. The objective of this project was to develop a web-based system for case reporting, data management and communications using the Internet and the NYSDOH's Health Provider Network (HPN). This system replaced a manual, paper reporting system. It was designed to streamline registry operations, reduce the reporting burden on hospitals and improve the quality and timeliness of registry data by taking advantage of new technologies.

Methods: The Health Provider Network (HPN) has been developed as a secure system for electronically collecting and distributing health related data. NYSDOH uses techniques which ensure that data exchanges between the HPN and providers are done in a secure fashion and also provide security for data. It is a HIPAA compliant system with a secure Internet site. The security system consists of servers' security protocols, firewall facilities and authentication procedures ensuring that only authorized users can access the data and services. The registry is maintained as a relational database on a Unix server using Sybase. The web applications were developed using software such as JAVA, PERL, Dreamweaver and SAS/Internet.

Results: The CMR has successfully converted 156 hospitals statewide from a manual, paper reporting system to an electronic Internet system using the NYSDOH's Health Provider Network. This web-based system allows hospitals two options: using an online data entry screen or a file upload procedure to report registry cases. Drop-down lists on the data entry screen along with data validation functions help ensure that reports sent electronically are complete and accurate. An interactive user menu system has numerous applications that enable CMR staff to maintain the database, process new case reports, review and code malformations and monitor hospital reporting. Extended editing capabilities and a transaction log were included for both CMR and hospital staff to check the completeness and accuracy of case reports. The HPN allows CMR staff and hospital users to communicate on-line via the web browser or e-mail. This innovative system enables CMR staff to query hospitals when a case report is incomplete or needs a more specific diagnosis.

Conclusions: The CMR's web-based system for case reporting, data management and communication offers a secure, cost-effective solution for participating hospitals to report birth defect cases. Authorized users need only a PC and a web browser such as Netscape or Microsoft Internet Explorer to access the system. Electronic reporting reduces the amount of paper, personnel and time necessary to comply with this mandatory process. Though the verification of data quality is in the beginning stages, electronic reporting should improve the accuracy, completeness and timeliness of CMR data as well. This transition is ongoing. CMR staff is currently working on new applications to improve and expand the system.

C1.9 New York State Congenital Malformations Registry

Evaluation of Referrals for Fetal Alcohol Syndrome (FAS) and Prenatal Alcohol Exposure at a Specialized Evaluation Clinic in Western New York

Deborah J. Fox, Charlotte M. Druschel, Luther K. Robinson

Objective: Prevalence rates for fetal alcohol syndrome (FAS), a preventable birth defect resulting from heavy maternal alcohol use, vary tremendously depending on study population characteristics and methods of case finding. FAS is more easily recognized in children ages 2-11 and is more difficult to diagnose in newborns. While state Birth Defect Registries differ in how children with FAS are identified, in the Congenital Malformations Surveillance Report published in Birth Defects Research (December 2007), reported rates of FAS, or ‘fetus or newborn affected by maternal alcohol use (760.71)’, vary from 0 to 3.02 per 10,000 live births. While some Registries seek cases up to one year of age, others have longer case-finding periods for certain birth defects including FAS.

Methods: Since the early 90’s, the Division of Genetics at Women and Children’s Hospital of Buffalo (WCHOB) has included a FAS Evaluation Clinic (FASEC) for individuals of all ages. Using referral data from 1995 through October 2007, we examined changes in referral patterns and mean age of referral for individuals suspected to have FAS or prenatal exposure to alcohol.

Results: 743 individuals were referred to FASEC with possible FAS or fetal alcohol exposure; 453 of these were residents of Erie County, New York, at time of referral. An average of 33 Erie County children/adults were referred annually, with a mean age at referral of 6.3 years (Median: 4.2 years; Range: 0-45.1 years). There was no trend towards increasing or decreasing number of annual referrals (Range: 7-52 referrals/year). Of these referrals, 394 individuals (87%) were seen at the clinic at a mean age of 6.1 years (Median: 4.1 years; Range: 0-45.1 years). Mean time from referral to first visit was 1.9 months. Annually, mean age at referral has not changed significantly although there is an upward trend to older ages of referral. In 1996, mean age at referral was 1.9 years (Range: 0-6.8 years) compared to the greatest mean age of 10.7 years in 2006 (Range: 0.4-45.1 years). Of the 394 individuals referred that were seen, 303 (76.9%) received diagnoses of FAS or fetal alcohol exposure. At the time of visit, these 303 individuals had a mean age of 5.5 years (Median: 3.5 years; Range: 0-39.5 years).

Conclusions: Mean age of referral for an FAS evaluation was older than the age cut-off used by most state Birth Defect Registries. Narrow surveillance periods for FAS from birth through the first few years of life are unlikely to capture a true picture of current FAS prevalence rates or trends. Evaluation of this referral population support the need for longer “case capture” periods for FAS surveillance efforts, including those at state Birth Defect Registries.

C1.10 New York State Congenital Malformations Registry

Identifying Unreported Cases Using the National Birth Defects Prevention Study Database

Zhen Tao, Ying Wang, , Philip K. Cross, Charlotte M. Druschel

Background: The New York State Congenital Malformations Registry (CMR) is a repository for case reports on children who are born or reside in New York State and are diagnosed before the age of two years with any structural, functional or biochemical abnormality determined genetically or induced during gestation and not due to birthing events. The CMR uses the method of passive case ascertainment that relies on case reporting by hospitals and physicians. Active follow-up is done to assure accuracy and completeness of case reporting by using hospital discharge data, review of hospital discharge summaries, on-site audits and CMR's web-based information query system. As one of the National Birth Defects Prevention Study (NBDPS) Centers, the New York Center began to ascertain birth defect cases since 1997. Children who reside in the defined study areas (8 counties in western New York and 7 counties in Lower Hudson Valley in New York State) and have selected major birth defects are identified by medical abstracters by visiting healthcare centers and hospitals to review and abstract case information from medical records. The objective of this study was to match the cases and compare diagnoses ascertained by the CMR and the NBDPS to identify unreported cases to the CMR.

Method: The NBDPS children born between 1998-2005 were selected and matched to the CMR database for the same birth years. A deterministic matching strategy was applied to identify all possible matches using combinations of identifying variables such as name, date of birth, date of discharge, medical record number and mother's name and address information. The NBDPS children who were not matched to the CMR were considered as new cases (unreported cases) and were added to the CMR. The NBDPS children who were matched to the CMR were carefully reviewed by CMR staff to identify additional diagnoses which were not reported to the CMR.

Results: A total of 2,250 children born in 1998-2005 from NBDPS database were identified for matching with the CMR data. There were 165 NBDPS children not matched to the CMR, i.e., they were not reported to the CMR. The unreported cases accounted for about 0.9 % of all CMR cases for the study year period (1998-2005) among the study population, the residents of the 15 counties in New York States. These unreported children were added to the CMR database. In addition, 362 NBDPS children were matched to the CMR database, but the diagnoses were partially matched, i.e., one or more diagnoses were missed in the CMR. These missed diagnoses were also added to the CMR. The results from further analysis of the 165 unreported NBDPS cases showed that 26 cases (15.8%) were ascertained from hospitals in New Jersey, the Genetics clinics at Children's Hospital of Buffalo and other healthcare centers; none of them routinely submit cases to the CMR. Septal heart defects, obstructive heart defects, and obstructive genitourinary defects accounted for majority of the unreported malformations.

Conclusion: There were very few NBDPS cases that were missed by the CMR (< 1% of the CMR cases). This strongly indicates that the case ascertainment of the CMR for the major malformations selected for the NBDPS is relatively complete, compared to the NBDPS that ascertains cases using an active case finding method.

C1.11 Texas Birth Defects Epidemiology and Surveillance Branch

Lessons Learned in Linking the Texas Birth Defect Registry with Newborn Screening Blood Spots for Research, 2002-2004

Lisa K. Marengo and Mark A. Canfield

Background and Objectives: Texas has a population based newborn screening program where every live born baby (381,441 in 2004) gets at least one and ideally two newborn blood spot screenings for metabolic disorders. Blood spots have the potential to enable a researcher to analyze DNA, proteins or other markers on a population basis. In Texas over 16,000 babies each year are born with at least one major congenital malformation. Linkage between the Texas Birth Defects Registry and the Newborn Screening laboratory database creates many research opportunities. This abstract will address some of the successes and challenges of linkage and research with the banked Newborn Screening blood spots.

Methods: Data were obtained from the Newborn Screening Laboratory and the Birth Defects Registry. Data were standardized and additional identification variables were pulled in from linking birth certificates with the Registry. Both deterministic (exact matching) and probabilistic strategies were tested for linking the blood spot data to the Registry cases. Deterministic methods were found to be more efficient for linking the two data sets, reducing the amount of clerical review necessary for linking true matches of individuals.

Results: One of the most surprising linkage variables found was phone number (75.4% exactly matched) which was even more productive than social security number (67.1% match). The addition of linked birth certificate information greatly enhances the linkage process by supplying additional identifiers. Variables most likely to produce an exact match are infant's birth date, city of residence, maternal first and last name as well as home phone number. Additional information will be presented.

Conclusions: Linkages of data sets containing infant data present unique but not insurmountable challenges.

C1.12 Texas Birth Defects Epidemiology & Surveillance Branch

Evaluation of Death Certificates for Finding Children with Birth Defects in Texas

Lisa K. Marengo, Mary K. Ethen, Mark A. Canfield

Background and Objectives: The Texas Birth Defects Registry conducts active surveillance in hospitals and birthing centers, but does not currently use Texas death certificates (DCs) to ascertain cases. The objectives of the study were to assess the feasibility and usefulness of adding Texas death certificates to augment our existing case-finding methods.

Methods: Texas DCs from 2004 and 2005 were searched to identify deaths that occurred in Texas before 1 year of age (infant deaths) among children born during 2004 who, according to information on the DC, were born in Texas or were Texas residents at the time of death. The multiple and underlying causes of death were examined to identify deaths with an ICD-10 code in the Q00-Q99 range (congenital malformations, deformations and chromosomal abnormalities). These were matched to cases in the Texas Birth Defects Registry. For those not found in the registry, registry case-finding logs were examined to determine whether staff had previously requested and reviewed hospital medical records (MRs) for the infant's birth and/or death, and if so, whether the child met the registry's case definition.

Results: There were 2437 infant deaths in Texas among children born in 2004 that met the remaining selection criteria. An ICD-10 code in the Q00-Q99 range (congenital anomalies) was the underlying cause for 547 infant deaths (22.4%) and was among the multiple causes of death for 620 infant deaths (25.4%). Of the 620 infant deaths with a congenital anomaly among the multiple causes of death, 488 (78.7%) matched to cases in the registry. Among the 132 (21.3%) that did not match to registry cases, staff had previously reviewed information at the birth and/or death hospital for 79 infants (12.7%) and determined that they did not meet the registry case definition. For 16 of the infant deaths (2.6%), registry staff had previously requested the children's medical records from the hospitals where the births and/or deaths occurred, generally on 3 occasions, but the hospitals were unable to provide the medical records for review. Thirty-seven infant deaths (6.0%) were not found in the case-finding logs, indicating registry staff have neither requested nor reviewed the birth or death hospital medical records for these children.

Conclusions: Existing case-finding methods of the Texas Birth Defects Registry detected 94.0% of the infant deaths with a congenital anomaly among the multiple causes of death: 78.7% matched to cases already in the registry, 12.7% were reviewed at the birth and/or death hospital and found not to meet the registry case definition, and 2.6% were requested but the hospitals at which the birth and/or death occurred were not able to provide the medical records for review. For 6.0% of infant deaths with a congenital anomaly among the multiple causes of death (n=37), there was no evidence registry staff requested or reviewed the medical records at the birth or death hospital. We are considering the feasibility of reviewing the medical records for these 37 infant deaths to determine whether they meet the registry case definition.

C1.13 Texas Birth Defects Epidemiology and Surveillance Branch

Clinical Differentiation of Patent Foramen Ovale and Secundum Atrial Septal Defect: A Survey of Pediatric Cardiologists

Jeffrey Owen and Angela Scheuerle

Background: Public health birth defect surveillance registries rely on health care provider diagnosis and definition of congenital anomalies. Major anomalies are likely to have consistent diagnosis across providers; however, definition of some more common, often minor, defects can be problematic. Of particular frustration are the transient neonatal heart findings: patent ductus arteriosus, patent foramen ovale and pulmonary artery branch stenosis. Under certain circumstances these findings may be considered true anomalies, patent foramen ovale (PFO) as a clinical finding overlap significantly with atrial septal defect (ASD) of secundum type, the latter being considered a true congenital malformation. Some criteria must be established to separate these conditions in case ascertainment. It is therefore helpful to understand the clinical definitions of patent ductus arteriosus and atrial septal defect.

Methods: Pediatric cardiologists in the greater Dallas area were surveyed by phone, fax and/or email and asked what criteria they used to distinguish a PFO from a secundum ASD. This was an open-ended question. No baseline parameters were suggested or introduced by the interviewer. Pediatric cardiology fellowship training was identified for each physician to examine the hypothesis that graduates of a given program would have the same diagnostic criteria.

Results: Responses were obtained from 22 of 23 pediatric cardiologists. Four measurement criteria were identified: size of the opening, presence or absence of a flap of septal tissue, appearance of the defect on echocardiogram and presence/absence/amount of blood shunting across through the opening. Though there was overlap, diagnostic criteria differentiating PFO and ASD varied among pediatric cardiologists. Two fellowship programs were well-represented by the respondent population. Eight respondents were trained at Fellowship A and five at Fellowship B. Place of fellowship training was not a strong indicator of which diagnostic criteria were used, even when graduates were in practice together.

Conclusions: The pronounced variability in clinical definitions will be a problem for birth defect surveillance and research based upon the resultant database. When different physicians use different diagnostic criteria for borderline defects, it is impossible to know whether a defect ascertained and coded with a standard protocol is the same across the population. Since it is unlikely that consistent diagnostic criteria can be put in place, the surveillance program is burdened with compensating for the variability.

C1.14 Texas Birth Defects Epidemiology and Surveillance Branch

Improving Data Quality Using Random Review of Birth Defect Coding - Results of 2 years of data

Ann Phelps

Background and Objectives: The Texas Birth Defects Registry conducts an active surveillance program with staff performing case finding and data abstraction in almost 200 hospitals in an area of 262,000 square miles. Staff are located in 5 offices and 5 sub-offices. Caseload has increased every delivery year from about 12,000 cases added to the Registry in 1999 to almost 17,000 in 2005. Staff use a web-based application called the Intranet Abstraction System (IAS) for data entry, birth defect coding, and quality assurance activities. After entry into the IAS, selected categories of cases are sent to one of three Clinical Reviewers for electronic feedback. Additionally, all records are eligible for a Diagnosis Code Review (DCR) step which randomly selects 10% of the records for birth defect coding review by clinicians. Registry staff regularly explore methods to increase efficiency and effectiveness in all aspects of its work. The DCR process and results are worthy of closer examination to determine efficiencies that can be added to the registry data collection and processing steps.

Methods: During record processing, DCR occurs as records are marked as “Complete”. Records are randomly selected for review by clinicians. A record is eligible for DCR even if the record had been previously clinically reviewed. DCR is performed by the same clinicians who handle the regular Clinical Review. To prevent bias, the selection of cases for DCR happens without input or influence by field staff or clinicians and a clinician cannot review a record for which (s)he was the last clinical reviewer. The clinician reviews the record, makes comments, and sends it back to the field staff as “DCR Complete” or “DCR Corrections”. Originally, 5% of records went through this step and in August 2006, the percentage was increased to 10% in order to more thoroughly monitor and evaluate data quality.

Results: During a 24 month period (January 2006 through December 2007), 2,800 records went sent for DCR, 2400 (86%) were marked as DCR Complete while 315 (12%) were marked as DCR Corrections. Another 26 records were determined to not be cases, and were deleted from the registry. Closer examination of the DCR Correction records can reveal interesting items. This poster will examine how frequently and what kind of changes were requested especially related to the birth defects listing (add, delete, change) and how frequently those birth defects changes were made (i.e., staff agreed with reviewer). The poster will also describe types of birth defects most frequently needing changes, how frequently the DCR is changing a CR instruction, as well as any changes needed in the data entry application and training needs to reduce errors

Conclusions: Examining ways to increase efficiency and effectiveness is crucial for a registry to be a good steward of taxpayer funds. The Texas Birth Defects Registry uses results of DCR analysis to increase staff awareness of process implementation problems, improve inter-clinical reviewer consistency, enhance technical training, modify procedures and make changes to the IAS. This is one step in our ongoing process of increasing the Registry data quality.

C1.15 University of South Florida Birth Defects Surveillance Program

Development of a Data Management and Report Generation System to Support Birth Defects Surveillance for the Environmental Public Health Tracking Program in Florida

Jason L. Salemi, Diana Sampat, Kimberlea W. Hauser, Russell Kirby

Objective: The Environmental Public Health Tracking (EPHT) initiative involves the ongoing collection, analysis, interpretation, and dissemination of data from environmental hazard monitoring and human exposure and health effects surveillance. In 2007, supported by funding through the Florida Department of Health, the Birth Defects Surveillance Program (BDSP) at the University of South Florida was responsible for developing and operating an active surveillance project to collect high quality data on 12 major birth defects in 14 counties across the state. To achieve its objectives for EPHT, the BDSP sought to enhance an existing Microsoft Access® database to develop an integrated database management system (DBMS) for use by a medical records abstractor. The DBMS would serve as a secure, user-friendly database that functions as a computerized case record (CCR) and is capable of aiding in case ascertainment, data collection, case classification, administrative record tracking, and report generation.

Methods: After soliciting feedback from abstractors, clinicians, and program coordinators, planned enhancements were designed to focus on usability, quality control, data collection, time-saving functionality improvements, automated tracking and requesting of medical records, and autogenerated reporting. Using an interface with SAS, ascertainment of potential cases has been improved to incorporate vital records, hospital discharge datasets, and electronic hospital case lists, which are automatically evaluated and imported into the database. Contact information for catchment hospitals is managed by the database and enables automated generation of letters and requests to Health Information Systems departments. Using feedback from clinical geneticists, we added fields to the CCR for selected genetic tests, consultations, ultrasounds, x-rays, and other diagnostic tests that would enable case review and classification. Additionally, the amount of information collected was expanded for non-cases to enable linkage to their respective vital records. The CCR incorporates real-time data validation checks and error messages, eliminating the previous need to run error reports and revisit records at day's end. Transaction and time logs were added to aid in documenting data edits and assisting abstractors in planning their time in the field.

Results: The BDSP has successfully used the new database management system to review over 1,300 records and abstract detailed information on nearly 600 cases for the EPHT program in 6 of the 14 catchment counties. The inclusion of vital records in case ascertainment resulted in an additional 7% of confirmed cases that would not have been identified by hospital case lists alone.

Conclusions: The changes made to the BDSP's database management system for EPHT have improved the way in which data is collected, enhanced the quality and completeness of the data, decreased procedural complexities associated with administrative tasks, and reduced the amount of paper, personnel, and time necessary to complete EPHT-related tasks.

Category 2: Birth Defects Risk Factors- Prescription and Over-the-Counter Medicines, Alcohol and Illegal Drugs, Infectious Agents, Other Hazardous Substances, Links to Environmental Data

C2.1 Arkansas Reproductive Health Monitoring System

Characterizing the Preterm, Birth Defect-Affected Population in Arkansas

Bridget S. Mosley, Weizhi Zhao, Charlotte A. Hobbs

Objective: Links between prematurity and birth defects have been observed in multiple epidemiological studies. Together, prematurity and birth defects constitute a major indicator for infant mortality and morbidity. The proportion and characteristics of the state's birth population born prior to 37 weeks gestation and affected by a birth defect has not previously been reported. The objective of this analysis is to characterize the population of preterm, birth defect affected population in the state of Arkansas. This analysis is the first phase of a project to link birth defect, vital statistics, and Medicaid data to further explore the impact prematurity and birth defects have on the birth population.

Methods: Data from the Arkansas Reproductive Health Monitoring System (ARHMS), the state's birth defect surveillance program, are routinely matched to natality data obtained by the Arkansas Department of Health. The proportion of premature infants that are affected by a birth defect will be determined by matching ARHMS, live birth and stillbirth data for the birth years 1998-2004. Specific type of birth defects among the premature population will be further evaluated. Comparisons between this premature, birth defect-affected population and other birth populations in the state (healthy term births and term birth defect-affected births) will be conducted. Race and ethnic-specific results are being investigated.

Results: Of the 261,703 infants born to Arkansas residents, approximately 10.9% were born prior to 37 weeks gestation. Preliminary analysis using the linked ARHMS-live birth data, indicate 6.3% of the infants born prior to 37 weeks gestation also were diagnosed with a birth defect before 2 years of age. The rate is more than 2.5 times the prevalence of birth defects (2.4%) among full term infants. Among all birth defect-affected pregnancies in the state, 23.8% resulted in a preterm delivery. This was significantly different from the preterm rate of 10.5% for births not affected by a birth defect ($p < 0.0001$). Additional analysis will further evaluate this preterm birth defect-affected population by birth defect type and maternal factors.

Conclusions: These results will provide clinicians and public health professions with vital information to discuss ways to achieve optimum pregnancy outcomes with obstetrical patients and communities. Building upon these results, linkage with Medicaid data will allow researchers to further investigate the impact prematurity and birth defects have on the birth population in the state.

C2.2 Centers for Disease Control and Prevention

Association of Paternal Age and Risk for Major Congenital Anomalies from the National Birth Defects Prevention Study, 1997-2004

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Objective: The objective of this study was to examine the associations between paternal age and birth defects of unknown etiologies.

Methods: Using 1997-2004 data from the National Birth Defects Prevention Study, we fit logistic regression models with paternal and maternal age as continuous variables while controlling for demographic and other factors.

Results: Elevated odds ratios representing per year increase in paternal age were found for cleft palate (odds ratio (OR) = 1.02, 95% confidence interval (CI): 1.00, 1.04), diaphragmatic hernia (OR = 1.04, 95% CI: 1.02, 1.06), right ventricular outflow tract obstruction (OR = 1.03, 95% CI: 1.01, 1.04), and pulmonary valve stenosis (OR = 1.02, 95% CI: 1.01, 1.04). At younger paternal ages, each year increase in paternal age correlated with increased odds of having offspring with encephalocele, cataract, esophageal atresia, anomalous pulmonary venous return, and coarctation of the aorta, but these increased odds were not observed at older paternal ages. The effect of paternal age was modified by maternal age for gastroschisis, omphalocele, spina bifida, all orofacial clefts, and septal heart defects.

Conclusions: Our findings suggest that paternal age may be a risk factor for some birth defects with complex etiologies.

C2.3 Department of Defense Birth and Infant Health Registry

Parental Stress, PTSD, and Infant Health Outcomes in U.S. Military Families

AT Bukowinski, AMS Conlin, IG Jacobson, GR Gumbs, CW Hoge, CJ Sevick, MAK Ryan, TC Smith

Background: Limited research suggests that parental prenatal stress may negatively impact infant health. In the military, parental stressors may include prolonged separation from family during deployments, in addition to stressors from combat and associated posttraumatic stress disorder (PTSD). Infant health outcomes of concern include preterm birth, birth defects, and growth deficiencies in utero or in infancy.

Methods: The Millennium Cohort is following a population-based sample of more than 150,000 US military personnel through 2022, using validated instruments to assess PTSD, alcohol and tobacco use, other health metrics, and military-related exposures. Linked to infant health outcomes from the Department of Defense Birth and Infant Health Registry, these data provide a unique opportunity to temporally investigate how parental stress and PTSD directly affect infant health, while controlling for confounding exposures of concern. A complementary analysis evaluates infant health after exposure to the acute stress of September 11, 2001 during pregnancy.

Results: No associations were found between exposure to the acute stress of September 11, 2001 during pregnancy and infant health outcomes. Analyses of the associations between parental stress or PTSD and preterm birth, birth defects, or growth deficiencies in utero or in infancy are ongoing.

Conclusions: Understanding the complex relationships between maternal stress and reproductive health remains challenging. Studies that are prospective, with adequate power, and valid assessments of exposure, outcomes, and confounding variables, may offer the greatest insight.

C2.4 National Birth Defects Prevention Network

Multi-State Study of the Epidemiology of Clubfoot, 2001-2005

Samantha Parker, Cara Mai, Matthew Strickland, Richard Olney, Russel Rickard, Robert Meyer, Lisa Marengo, Ying Wang, and S. Shahrukh Hashmi for the National Birth Defects Prevention Network

Background and Objectives: Clubfoot is a relatively common birth defect, with a prevalence of approximately 1 per 1,000 live births. The etiology of most types of clubfoot remains largely unknown. Genetic, maternal, and environmental risk factors have all been linked to the development of clubfoot. Studies of the prevalence and risk factors for clubfoot in the United States have been limited to state-specific data. This study pooled data from several states to estimate the prevalence of clubfoot and investigate hypothesized risk factors.

Methods: A call for data, sponsored by the National Birth Defects Prevention Network Data Committee, was sent to state population-based birth defects surveillance programs inviting them to participate and submit record-level case data on clubfoot, including talipes equinovarus or clubfoot not otherwise specified, for the years 2001-2005. Participating programs included Metropolitan Atlanta, Colorado, New York, North Carolina, Rhode Island, Puerto Rico, Tennessee, and Texas. Infants with neural tube defects, bilateral renal agenesis, and certain other major malformations related to club foot were excluded from the case group. A random sample of ten controls per case, without major congenital anomalies, limited to live births within the same birth year was selected from birth certificate data. Additional infant and maternal characteristics such as demographic data were collected from birth certificates. Prevalence was calculated by pooling the state-specific data. Conditional logistic regression was used to investigate the association between exposures of interest and clubfoot. Geocoded residence information and census tract identification were provided by select sites, and will be used in investigating geographic variations and sociodemographic factors in subsequent analyses.

Results: The overall prevalence of clubfoot was 1.25 per 1,000 live births; 1.32 among both non-Hispanic whites and Hispanics, and 1.07 per 1,000 live births among non-Hispanic blacks. Between 2001 and 2005, the prevalence of clubfoot increased from 1.17 to 1.39 per 1,000 live births. Male infants were more likely to be affected by clubfoot [OR: 1.67 (1.57, 1.77)]. Infants with clubfoot were also more likely to be pre-term and weigh less than 2500 grams. Mothers of cases were significantly more likely to be younger than 23 years old, single, and have less than 12 years of education. Mothers who reported smoking were significantly more likely to have a child with clubfoot compared to mothers who did not report smoking [OR: 1.48 (1.35, 1.62)]. Diabetes, including both pre-gestational and gestational, was associated with having an infant affected by clubfoot in our data [OR: 1.57 (1.32, 1.86)]. Women enrolled in Medicaid were also significantly more likely to deliver an infant with clubfoot in the bivariate analysis [OR: 1.35 (1.23, 1.49)].

Conclusions: This study is the first to report the prevalence of clubfoot using data from several birth defect registries. Our findings are consistent with previously reported associations between clubfoot and smoking. The significant associations found between clubfoot and maternal education, young maternal age, and Medicaid status may indicate a sociodemographic component of clubfoot that should be further investigated with the availability of census tract identification.

Disclaimer: The findings and conclusions in this report are those of the author(s) and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

C2.5 National Center on Birth Defects and Developmental Disabilities, CDC

Association of Periconceptional Ginkgo Biloba Use With Selected Major Birth Defects

CS Broussard, C Louik, J Reefhuis, CA Moore, MA Honein

Objective: Whereas previous literature has advised caution for the use of ginkgo biloba in pregnancy, information from which to guide women and their health care providers about the risks or safety associated with ginkgo biloba use during pregnancy is very limited. It has been suggested that exposure to aspirin, other non-steroidal anti-inflammatory drugs, or other blood thinners in conjunction with ginkgo biloba may result in harmful drug interactions. We investigated whether reported periconceptional use of products containing ginkgo biloba was associated with any specific birth defect or class of defects.

Methods: The National Birth Defects Prevention Study (NBDPS) is an ongoing multisite case-control study that uses a maternal telephone interview. Specific questions about herbal use were initiated in mid-2000, and our analysis included data for women with estimated dates of delivery from 1998-2004. Exposure was defined as maternal use of a ginkgo biloba product between the month before pregnancy and the end of the first trimester. We excluded mothers with preexisting diabetes. Logistic regression analysis was performed to estimate crude odds ratios for 8 individual birth defects and 7 classes or combination groups of birth defects that had at least 3 exposed cases.

Results: Among 4,228 mothers of NBDPS control infants who responded to the herbal question, 19 (0.45%) reported using a product containing ginkgo biloba between 1 month before and 3 months after conception. Among 12,517 mothers of case infants, 52 (0.41%) reported ginkgo biloba use in the same exposure time window. Reported products included ginkgo biloba extract alone as well as multivitamins and multi-component herbal products containing ginkgo biloba. None of the crude associations were statistically significant, but odds ratios (95% confidence intervals) were elevated above 1.5 with wide confidence intervals for the class of neural tube defects: 1.7 (0.6, 4.5), the ventricular septal defect + atrial septal defect association: 1.8 (0.3, 6.0), and the individual defects spina bifida: 2.0 (0.5, 5.9), cleft lip: 1.8 (0.3, 6.0), and hypospadias: 1.7 (0.4, 6.2).

Conclusions: Maternal self-reported periconceptional exposure to ginkgo biloba was relatively uncommon. None of the birth defects studied were associated with periconceptional ginkgo biloba use. Our results need to be confirmed by other studies with larger sample size; in particular, interactions between ginkgo biloba and other drugs should be evaluated since the current sample size was insufficient to evaluate drug interactions.

C2.6 Texas Birth Defects Epidemiology and Surveillance Branch

Variation in Pregnancy-Related Risk Behaviors and Maternal Conditions among United States and Foreign Born Mothers by Race/Ethnicity

Tunu Ramadhani, Mark A. Canfield, D. Kim Waller, Marjorie Royle, Adolfo Correa, and the National Birth Defects Prevention Study

Objective: Pregnancy related risk behaviors and maternal illnesses of foreign born mothers appear to be different from mothers born in the US. US-born mothers are reported to have greater rates of the risk behaviors and maternal illness conditions during pregnancy. The National Birth Defects Prevention Study (NBDPS), a multi-state and population-based case-control study, provides a unique opportunity to examine further these differences in a large and more varied population than in previous studies. This study examines the relationship of selected pregnancy related risk factors and mothers' national birthplace among controls.

Methods: We used the NBDPS controls from October 1997 to December 2003. We stratified maternal race/ethnicity into non-Hispanic White, Hispanic and non-Hispanic Black, and birthplace into US-born and foreign-born. Within race/ethnicity strata we examined socio-demographic characteristics (maternal age at conception, years of education attained, household income and parity), maternal health conditions (pre-existing diabetes, gestational diabetes, hypertension, and body mass index) and behavioral risk characteristics (alcohol consumption, binge drinking, smoking, initiation of prenatal care and folic acid use during pregnancy, as well as pregnancy intent and interval to index pregnancy). Using logistic regression, we calculated crude and adjusted odds ratios and 95% confidence intervals, using the group "US-born" as a referent.

Results: Foreign born non-Hispanic whites were more likely to be 35+ years of age [OR=3.39, (1.04, 11.04)] and less likely to have attended 12+ years of formal education [OR=0.32, (0.13, 0.78)] compared with U.S.-born counterparts. However, with respect to behavioral characteristics, the populations were similar. Foreign-born Hispanic mothers were much older; less educated, and had a lower household income than their U.S.-born women. Though, foreign born Hispanic mothers were less likely to drink [OR=0.58, (0.43, 0.79)] or do binge drinking [OR=0.51, (0.28, 0.91)], smoke [OR=0.43, (0.25, 0.75)], or use illicit drugs [OR=0.15, (0.04, 0.55)] and they were almost twice as likely to have an intended pregnancy. US-born Black women were more likely to be <20 years old compared with foreign-born Black women. Foreign-born Black mothers were much less likely to smoke [OR=0.10, (0.01, 0.75)], and use periconceptional folic acid supplements [OR=0.30, (0.14, 0.66)]. Overall, foreign born mothers were less likely to have high blood pressure during pregnancy, less likely to be obese [OR=0.43, (0.33, 0.58)], but more likely to be underweight [OR=1.65, (1.19, 2.29)]

Conclusions: Compared to US-born mothers, foreign-born mothers' exhibit pregnancy related behaviors and profiles of maternal conditions that tend to favor healthier outcomes. Whether such profiles compensate for the risk of adverse pregnancy outcomes associated with lower socioeconomic status remains to be determined.

C2.7 Texas Birth Defects Epidemiology and Surveillance Branch

Are Less Acculturated Hispanic Parents at Higher Risk for Having Offspring with Anencephaly and Spina Bifida?

MA Canfield, T Ramadhani, GM Shaw, DK Waller, SL Carmichael, B Mosley, R Olney, and the National Birth Defects Prevention Study

Objective: The prevalence of neural tube defects (NTD) (anencephaly and spina bifida) is higher in Hispanics, relative to non-Hispanic whites. Among Hispanics, the prevalence has been shown to vary by “acculturation” factors, such as parents’ country of birth, duration of residence in the U.S., and predominant language. Some investigators have hypothesized that there is increased NTD risk for less acculturated Hispanics (i.e., those born outside the U.S., those who moved here more recently, and/or those who speak primarily Spanish). The National Birth Defects Prevention Study provides enough detail on these variables for both mothers and fathers to examine this hypothesis further

Methods: We analyzed data from Hispanic and non-Hispanic white mothers who completed the interview and had expected delivery dates from October 1998 through 2003. Hispanics were stratified by country of birth for each or both parent(s) (U.S., Mexico/Central America, other); length of time in the U.S. (<5 vs. 5+ years); and predominant language (English vs. Spanish). Crude odds ratios (cOR) and 95% confidence intervals were calculated, using whites as the referent group.

Results: Our dataset consisted of 206 parents of cases of anencephaly, 473 cases of spina bifida, and 4,133 non-malformed controls. For U.S.-born Hispanic parents, there was no significant elevated risk for spina bifida, relative to whites (cOR range=1.2 to 1.3). However, crude odds ratios for Hispanic parents born in Mexico or Central America were much higher and significant (range=2.2 to 3.0). If both parents were born in Mexico/Central America and they were also lived in the U.S. <5 years, the cOR was 3.3 (95% CI=1.5-7.4), compared to white parents. For Hispanics who primarily spoke or interviewed in English, cOR for spina bifida were modestly elevated and mostly non-significant, relative to whites (cOR range=1.2 to 1.4). Odds ratios were considerably higher and significant for Hispanic mothers who interviewed in Spanish, or for mothers and fathers for whom the predominant language at home was Spanish (cOR range=1.7 to 2.2). For anencephaly, the risk for both U.S.-born Hispanic mothers and English speaking was roughly twice that of white mothers. For example, if both the mother and father were U.S.-born Hispanic (vs. both being white), the cOR for anencephaly was 2.3 (95% CI=1.4-3.9). If fathers were born in Mexico/Central America, cOR for fathers or both parents were higher (range=2.5-2.8).

Conclusions: Relative to whites, odds ratios were generally elevated for Hispanic mothers and fathers with less acculturation to the U.S. and presumably closer ties to their country of origin, as demonstrated by parents’ birth outside of the U.S. (i.e., Mexico/ Central America) and Spanish being the predominant language. For anencephaly, but not spina bifida, U.S.-born and English-speaking Hispanic parents (who some might consider “more acculturated”) were also at increased risk, compared to whites.

C2.8 Texas Birth Defects Epidemiology and Surveillance Branch

Birth Defects in Non-Hispanic Blacks: Are They Related to Mothers' Nativity?

Tunu Ramadhani, Vanessa Short, Mark A. Canfield, D. Kim Waller, Marjorie Royle

Objective: Few studies have examined the risk of birth defects among foreign-born Hispanic mothers compared with their US-born counterparts or non-Hispanic white mothers. To our knowledge there is no literature which reported nativity and birth defects in non-Hispanic black mothers. We analyzed the association between birth defects and maternal birth nativity among black mothers, using the National Birth Defects Prevention Study (NBDPS), a multi-center population-based case-control study, from October 1997 to December 2004.

Methods: The NBDPS collects data on almost 30 different birth defects, country of birth and parental socio-demographic characteristics. We used questions on country of birth and socio-demographic characteristics and calculated percent distributions of selected maternal characteristics. Using logistic regression, we calculated odds ratios and their 95% confidence intervals, and assessed the relationship between foreign-born nativity and selected birth defects, using US-born non-Hispanic black mothers as referent group. All analyses were adjusted for mother's age at conception, body mass index, education and study site.

Results: Among all 2,386 black mothers in the study (1707 case mothers and 679 control mothers), 87% of mothers were U.S. born, 11% of mothers were foreign born, and the remainder (2%) had missing information on birth place. For foreign-born control mothers, the countries of birth reported most often were Jamaica, Haiti, and Nigeria. Overall, foreign-born mothers were more likely to be 25+ years old, to be more educated, to report higher annual household incomes, and have at least one previous child. We did not find statistically significant associations between the selected birth defects and birth nativity among these mothers. However, foreign-born non-Hispanic black mothers had approximately twice the risk of delivering babies with hydrocephalus (OR=2.04 95%CI=0.79 - 5.28), d-transposition of great arteries (OR=2.81, 95% CI=0.94 - 8.39), and all cardiac septal defects combined (OR=1.83, 95% CI=0.79 - 4.21) compared with U.S.-born black mothers. These mothers also had a 50% higher risk of delivering infants with hypoplastic left heart syndrome (OR=1.52, 95% CI=0.59 - 3.89), diaphragmatic hernia (OR= 1.52, 95% CI=0.53 - 4.35) and all cardiac associations combined (OR=1.50, 95% CI=0.79 - 2.86). But, foreign-born black mothers were 52% less likely to deliver babies with cleft lip+/- palate (OR=0.48, 95% CI= (0.18 - 1.27) compared to their U.S.-born counterparts.

Conclusions: This is an exploratory research on this important topic. The differences in the occurrence of birth defects among different non-Hispanic black nativity groups might be due to differences in ascertainment or differences in cultural norms and behavioral characteristics.

C2.9 Texas Birth Defects Epidemiology and Surveillance Branch

The Association Between Periconceptional Maternal Fish Consumption and Birth Defects

Tunu A. Ramadhani, Michelle Steck, Suzan Carmichael, Jean Brender, Amy Case, Angela Scheuerle and the National Birth Defects Prevention Study

Objective: Maternal fish consumption is useful in fetal growth and development due to the less saturated and high unsaturated fats, proteins and essential nutrients. On the other hand, maternal fish consumption may expose the fetus to environmental contaminants such as polychlorinated biphenyls, dichlorodiphenyl dichloroethylene and methylmercury, which have been linked to neuro-developmental problems in human offspring and structural malformations in animal fetuses.

Methods: The National Birth Defects Prevention Study (NBDPS) collects data on approximately 30 different birth defects; maternal foods consumed one year prior to conception and socio-demographic characteristics. We used logistic regression and calculated odds ratios and their 95% confidence intervals (CI), to assess the relationship between periconceptional maternal fish consumption and the occurrence of birth defects in the NBDPS population.

Results: In total, there were 15,884 cases and 5,958 controls, out of which 68% ate 3-5oz of fish for at least once a month. Adjusted odds ratios (aOR) suggested that compared with mothers who did not eat or ate fish for less than once a month, mothers who ate 3-5oz of fish, 1-3 times/month were significantly protected for oral clefts (aOR=0.82, 95% CI=0.73-0.93), anomalous pulmonary venous return (aOR=0.54, 95% CI=0.36-0.81) and anorectal atresia/stenosis (aOR=0.78, 95% CI=0.62-0.98). However, fish consumed more than 4 times per month was a significant risk factor for delivering babies with perimembranous ventricular septal defects (aOR=1.25, CI=1.03-1.51) and amniotic band syndrome (aOR=1.60, 95% CI=1.01-2.55). Furthermore, eating fish at any level elevated the occurrence of encephalocele (aOR ranged from 1.50 to 1.72, but not significant).

Conclusions: For mothers who are planning to have babies, eating 3-5oz of fish, 1-3 times per month might be protective for some birth defects, but it might confer risk if consumed high amounts.

Category 3: Birth Defects Rates and Trends- Graphical Presentation of Data, Statistical Assessment (Simple of Complex), Cluster Evaluations

C3.1 Arizona Birth Defects Monitoring Program

Characteristics of Race Specific Rates of Spina Bifida in Arizona, 1989-2004

Tim Flood, Viral Joshi, Christopher Tex

Objective: The Arizona Department of Health Services (ADHS) has received requests for definitive information concerning the rate of Spina Bifida. In this project we ask whether the rate of Spina Bifida is increasing statewide and whether race/ethnicity plays a role. Data collected by the ADHS Birth Defects Monitoring Program (ABDMP), which tracks the incidence of neural tube defects, shows that approximately 34 babies are born in Arizona each year with Spina Bifida.

Methods: From 1989 to 2004, the ABDMP has registered the count of infants diagnosed with various birth defects, including Spina Bifida. Cases that are live born or stillborn are registered into the ABDMP. To address the concerns about rates, we queried the databases of the ABDMP for cases of Spina Bifida (741.000-741.930). We used these counts to generate the birth prevalence rate of this condition, by year and race/ethnicity for births occurring in Arizona.

Results: There were 369 cases of Spina Bifida for the years 1994-2004. In this time period the average rate of Spina Bifida for all races in Arizona was 4.20 per 10,000 live births. There were 26 Native American cases of Spina Bifida for the years 1994-2004 (average rate 4.52 per 10,000 live births). There were 162 Hispanic cases of Spina Bifida for the years 1994-2004 (average rate 4.95). There were 149 White, non-Hispanic cases of Spina Bifida for the years 1994-2004 (average rate 3.44). The small number of cases for Native Americans between 1994 and 2004 make yearly rates unstable. No clear temporal trend was identified for the Hispanic and White, non-Hispanic population between the years 1994-2004. Prior to FDA-mandated fortification (between 1989 and September 30, 1996), there were 274 cases of Spina Bifida. The rate for this time period was 4.95 per 10,000 live births. When analyzed by race/ethnicity for the pre-folic acid fortification, the rates (1989-1996) among the Black, Hispanic, Native American, and White, non-Hispanic population were 2.60 (95% CI: 0.84-6.07), 5.71 (95% CI: 4.57-6.84), 5.60 (95% CI: 53.59-8.33), and 3.77 (95% CI: 3.09-4.46) per 10,000 live births, respectively. Post fortification (between October 1, 1998 and December 31, 2003), there were 209 cases of Spina Bifida. The rate for this time period was 4.16 per 10,000 live births. When analyzed by race/ethnicity for the post-folic acid fortification, the rates (1999-2004) among the Black, Hispanic, Native American, and White, non-Hispanic population were 1.78 (95% CI: 0.37-5.19), 4.97 (95% CI: 3.99-5.95), 5.13 (95% CI: 2.99-8.22), and 3.10 (95% CI: 2.40-3.81) per 10,000 live births, respectively.

Conclusions: Our data suggest that Hispanics and Native Americans have rates that are statistically elevated compared to that of White non-Hispanics for the pre- and post-folic acid fortification period.

C3.2 Centre of the International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR Centre), Roma, Italy

Validity of Registration of Down Syndrome in the International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR)

Mastroiacovo P, Leoncini E, ICBDSR Down Syndrome Working Group

Background: Worldwide, there are many birth defects “registries” or “surveillance systems”, often as part of national and international networks. A shared objective for these registries is to provide epidemiological surveillance of new epidemics or clusters of birth defects, report on changes in prevalence related to, for example, a new medical intervention, and to provide a basis for etiological research on birth defects. To serve this purpose, it is crucial to ensure that data provided by a birth defect registry are valid and reliable. We propose a simple method to evaluate the validity of Down Syndrome (DS) data in a surveillance system. The method is based on the assumption that the maternal age specific rates of DS are not affected by temporal, ethnic, geographical or environmental factors with a possible exception for a few ethnic groups.

Methods: We used data on DS collected by surveillance system members of the International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR) for the period 2001-2005. For each surveillance system we have first computed the number of observed cases by each maternal age interval: the sum of subjects with the DS in livebirths, stillbirths and termination of pregnancies. For those surveillance systems where Terminations of Pregnancies (ToPs) are permitted we computed the “adjusted” observed number of cases, taking into account the prenatal losses that would have occurred if prenatal diagnosis and ToP had not been done. Then we have computed the livebirths expected cases: the sum of cases obtained multiplying the total number of births in each maternal age interval by the reference rates given in the “derived rates” column of Table II of Hecht and Hook (1996), based on studies judged to have “near complete” ascertainment of livebirth DS.

We have computed the adjusted observed/expected ratio (AO/E ratio) for each maternal age group and for the maternal age group 25-44 years. The 25-44 years maternal age AO/E ratios were computed with their 95% confidence interval (CI). AO/E ratios with the upper confidence limit < 1.0 suggest an under-registration while AO/E ratios with the lower confidence limit > 1.0 suggest an over-registration.

Results: During 2001-2005, the total number of cases of DS ascertained by 29 ICBDSR surveillance systems in the maternal age group 25-44 years was 12,418 among a total of 6 millions livebirths. There were nine surveillance systems with an AO/E ratio including 1.00 in their CI, two surveillance systems with an AO/E ratio statistically significant above 1.00, and eighteen with an AO/E ratio statistically significant lower than 1.00. There was no evidence of heterogeneity in any surveillance system when the AO/E ratios were analyzed by single year or by five year maternal age intervals.

Conclusions: Evaluation of the validity of registered and disseminated data on the prevalence of birth defects is an essential issue in each surveillance system. It may suggest the need for more resources and support improve data collection and obtain the most reliable data. The value of the approach proposed in the present paper is that can be used in any surveillance system and requires only limited extra effort. Validity of DS registration may be also a good indication of the accuracy of data in the surveillance system for other birth defects.

C3.3 Department of Defense Birth and Infant Health Registry

Infant Health in US Military Families: The Department of Defense Birth and Infant Health Registry, 1998–2006

AS Conlin, GR Gumbs, IG Jacobson, CJ Sevick, AT Bukowinski, KJ Snell, TC Smith

Objective: The United States Department of Defense (DoD) is challenged with monitoring and protecting the health of its service members and their families. Concerns exist that some military-unique exposures, such as deployment, may pose a risk to reproductive health. The global geographic distribution of service members prohibits state surveillance systems from completely capturing their reproductive health data. The DoD Birth and Infant Health Registry is a global surveillance system designed to evaluate birth defects and other infant health outcomes among children born to military families.

Methods: Inpatient and outpatient diagnostic data are obtained from military and civilian medical centers to capture births and health outcomes in the first year of life among infants born to US military families. Birth and diagnostic data are matched with parental demographic, occupational, and exposure data. A sample of original records is reviewed for case validation.

Results: More than 800,000 infants were born to military families in all 50 states and more than 20 foreign countries between 1998 and 2006. The prevalence and types of major birth defects in military infants are consistent with those found in the general US population. A variety of parental exposures have been examined to date including smallpox and anthrax vaccination, and deployment to the wars in Iraq and Afghanistan. In addition to birth defects, the Registry also examines other health outcomes including preterm birth, in utero and infant growth deficiencies, infant sex ratios, inflicted traumatic brain injury in infancy, and infant neoplasms, including malignancies.

Conclusions: Drawing from a variety of robust data sources, the DoD Birth and Infant Health Registry assesses the prevalence of birth defects and other health outcomes among infants born to military families. Global monitoring of outcomes and the ability to link to parental military exposures are unique features of the Registry. Ongoing analyses exploit these capabilities by focusing on birth defects among infants with gestational exposure to specific geographic regions, and infant health outcomes subsequent to parental combat related PTSD.

C 3.4 Louisiana Birth Defects Monitoring Network

Results from the Initial Year of Birth Defects Surveillance in Louisiana (2005)

Kay Webster, Tri Tran, Susan Berry

Objective: The Louisiana Birth Defects Monitoring Network (LBDMN) was established by legislative mandate in 2001. LBDMN is an active, limited population-based surveillance system that tracks the occurrence of birth defects and related conditions in children ages 0–2. Data collection was initiated in January 2005 in four regions of the state: Baton Rouge metropolitan (Region 2), Lake Charles/southwest LA (Region 5), New Orleans metropolitan (Region 1), and Shreveport/northwest LA (Region 7). The purpose of this project is to present results of analyses conducted on data from the first year of birth defects surveillance in Louisiana.

Methods: Data were obtained from the LBDMN registry, with additional information provided by linkage with birth certificate and infant death data from Louisiana Vital Records. Registry data included liveborn infants who met LBDMN case definition criteria. Because surveillance coverage for Region 1 was determined to be inadequate for 2005, analyses were limited to births among residents of Regions 2, 5 and 7 (n=19,990). Using SAS, analyses were conducted to (1) calculate frequencies of birth defects by body system; (2) estimate rates (per 10,000 live births) and 95% confidence intervals for the top ten birth defect diagnoses; (3) examine the association between having a birth defect and maternal characteristics and birth outcome, including maternal race, maternal age, preterm birth, low birth weight, and infant death.

Results: Surveillance coverage for 2005 was determined to be 42.5% of total births. Births in Regions 2, 5, and 7 represented 32.4% of total births. Cardiovascular malformations (CVM) were the most common type of birth defect (42.8%), followed by genitourinary (27.2%) and gastrointestinal malformations (12.3%). Atrial septal defect (ASD) was the most common birth defect (rate=64.03, CI: 52.94–75.12). The rate of all birth defects in Regions 2, 5 and 7 was 235.12 (CI: 213.86–256.37). Infants of white mothers were more likely to have a birth defect when compared to black mothers (OR=1.50, CI: 1.24–1.82). Mothers of advanced maternal age (35+ years) were more likely to have an infant with a birth defect when compared to mothers age 20–34 (OR=1.48, CI: 1.12–1.97). Infants with birth defects were six times more likely to be born very preterm (<32 weeks gestation) than infants without birth defects (OR=6.09, CI: 4.51–8.22), and 2.5 times more likely to be born preterm (32–36 weeks gestation) (OR=2.69, CI: 2.15–3.37). Similarly, infants with birth defects were more likely to be of very low birth weight (<1500 grams) (OR=5.99, CI: 4.36–8.24) and of low birth weight (OR=3.12, CI: 2.49–3.91). Infants with birth defects were nearly nine times more likely to die within their first year of life than infants without birth defects (OR=8.77, CI: 5.90–13.04).

Conclusions: About 2.4% of children in the study had some type of birth defect; CVM were by far the most common, with 42.8% of case children having at least one CVM. Infants born to women over age 35 and infants born to white mothers were more likely to be born with birth defects. Infants with birth defects were at significantly increased risk of infant death, of being born prematurely, and of being born low birth weight. This research presents results of analyses conducted on data from the first-ever year of birth defects surveillance in Louisiana. While these findings cannot be used to draw conclusions about Louisiana as a whole, they do provide useful information on the burden of birth defects in three of the most populous regions of the state.

C3.5 National Center on Birth Defects and Developmental Disabilities, CDC

Demonstration of Web Dashboard Concepts – MACDP

Clinton J (CJ) Alverson

Objective: A web-based dashboard is an interface that presents multiple elements of information in ways that promote a natural understanding of the subject at hand. A dashboard displays multiple facets of information, usually in an interactive manner. We will demonstrate the utility of the dashboard as a method for displaying multiple facets of information about birth defects.

Methods: We will generate descriptive tables using selected MACDP data, as well as conventional and sparkline graphics. Our dashboard will incorporate tables and graphics with multiple layers of detail. The dashboard elements will be hyperlinked to more detailed information, enabling the user to drill down to increasingly detailed views of selected facets of information.

Results: We will present a poster describing the dashboard process, and will provide a PC-based demonstration of the dashboard.

Conclusions: The dashboard concept is relatively new, but is popular as an interactive mode of presenting business information. The dashboard presents information at multiple levels of detail and focus. There is a rich array of technical support for the implementation of dashboard technology, but the use of dashboards in public health applications is modest. In our setting, dashboard technology will allow the rapid dissemination of birth defect information directly to our stakeholders. Moreover, the interactive nature of the technology allows the user to customize their information.

C3.6 National Center on Birth Defects and Developmental Disabilities, CDC

Case Fatality Rates among Critical and Non-critical Cardiac Phenotypes in Infants with Down Syndrome

T. Riehle-Colarusso, M. Shin, A. Correa

Objective: Congenital heart defects (CHD) are an important prognostic indicator for survival among children with Down syndrome (DS). Phenotype severity may be an important factor associated with mortality. Existing surveillance coding systems do not allow for detailed severity categorization. Thus, this study utilized a clinically-based CHD classification system to describe differences in the case fatality rate (CFR) of critical and non-critical CHD phenotypes among infants with DS.

Methods: The CHD of infants born from 1979 through 2003 with DS and CHD in the Metropolitan Atlanta Congenital Defects Program (MACDP) were classified using nomenclature adopted from the Society of Thoracic Surgeons. Atrioventricular septal defect (AVSD) and non-AVSD cardiac phenotypes were further categorized into critical or non-critical according to a hierarchical schema. CFR rates for each group was calculated and compared to the CFR for non-critical, non-AVSD group using case fatality rate ratios (CFRR).

Results: There were 921 live births with DS from 1979-2003, of which 394 had CHD. Among 165 with critical CHD, 144 (87%) had AVSD, while among 229 non-critical CHD, 184 (80%) had non-AVSD. Furthermore, 76% (144/189) of all AVSD were critical. The highest CFR was for infants with DS and critical AVSD (24 deaths out of 144 cases = 16.7), while the lowest CFR was for those with non-critical non-AVSD (6 deaths out of 184 cases = 3.3). Compared to infants with non-critical, non-AVSD, the CFR for infants with critical AVSD was five times higher (CFR Ratio [CFRR]=5.11, 95% confidence interval [CI]: 2.14-12.17) and the CFR for those with critical non-AVSD was four times higher (CFRR=4.3, CI: 1.18-16.24)

Conclusion: AVSD is a common CHD among infants with DS. In this study, the majority of infants with DS and AVSD had critical phenotype, which had the highest CFR. Utilizing standard clinical nomenclature to categorize CHD by critical and non-critical phenotypes is useful to understand which infants with DS may be at greater risk for mortality.

C3.7 Oklahoma Birth Defects Registry

Diagnosis of Birth Defects by Organ Systems in an Active Surveillance Birth Defects Registry

Kay Pearson, Kara Wilbur

Background: The Oklahoma Birth Defects Registry (OBDR) began statewide data collection in 1994. In 2000, the OBDR began prenatal ascertainment of birth defects at the Prenatal Assessment Center at the Oklahoma University Medical Center and added the Perinatal Center of Oklahoma in 2005. Over the years, ascertainment of cases through outpatient clinics has expanded. The objective is to review when birth defects are diagnosed to provide trends in care ascertainment and treatment of birth defects in Oklahoma.

Methods: Birth defects from 1994 through 1996 were divided into the following organ systems: central nervous system, ear/face/neck, eye, heart, respiratory, cleft lip/cleft palate, digestive, genital, urinary, musculoskeletal and chromosomal. Demographic variables of sex and race were determined by year for each organ system, along with pregnancy outcome: live birth, stillbirth and terminations. Timing of the birth defects diagnosis was examined by organ system and year to determine trends in case ascertainment over time. The three diagnostic timing categories used were prenatal, birth hospital, and after discharge from the birth hospital.

Results: As expected, prenatal diagnosis of all birth defects increased over the thirteen-year time period reviewed. Digestive system defects experienced the most dramatic shift in diagnosis. In 1994, only 8.11 percent of the digestive cases were diagnosed prenatally, 26.58 percent in the birth hospital and 65.32 percent were diagnosed after the child was discharged from the birth hospital. By 2006, prenatal diagnosis increased to 22.22 percent, a 2.7 fold increase. Ear/face/neck, heart, and musculoskeletal defects all had a two-fold increase in prenatal diagnosis. Cleft lip/palate and genital defects experienced an increase in prenatal diagnosis of 1.7 times. Prenatal diagnosis increased 1.5 times for central nervous system defects. Prenatal diagnosis of respiratory, urinary and chromosomal defects remained stable over the thirteen-year period.

Conclusions: Prenatal diagnosis of birth defects allows health care providers and families' time to prepare for the birth by arranging delivery at a tertiary hospital with a neonatal intensive care unit staffed by pediatric specialists to provide immediate medical care. Families can talk to specialists, support groups and families of children with similar defects before their baby is born. This can help them understand the medical issues, what treatment is needed and how the family may be impacted. The OBDR has worked with prenatal diagnostic centers on neural tube defect recurrence prevention, but needs to explore opportunities for assisting families impacted by other birth defects during the prenatal period.

C3.8 Pregnancy to Early Life Longitudinal (PELL) Down Syndrome Project

Using a Unique Linked Data System to Assess Live Birth Prevalence, Co-Occurring Birth Defects, and Case Fatality Rates among Infants with Down Syndrome in Massachusetts, 2001-2005

Taletha M. Derrington, Sara M.A. Donahue, Judith Weiss, Milton Kotelchuck, Angela Lin, Tiffany Colarusso, Cathy Higgins, Adolfo Correa, and members of the PELL Down syndrome project team

Objective: To describe the prevalence of Down syndrome (DS) among infants born to Massachusetts residents during 2001-2005 by the presence of major congenital heart defects (CHD) and/or other major non-cardiac birth defects (OMBD), and to compare case fatality rates among these infants using a unique linked population-based data system. The Massachusetts Birth Defects Monitoring Program (MBDMP) regularly publishes surveillance data on birth prevalence of infants with DS. However, more detailed information on co-occurring congenital anomalies and mortality has not previously been presented.

Methods: Data were derived from the Pregnancy to Early Life Longitudinal (PELL) Data System, which links MBDMP data to birth certificate, hospital delivery discharge, and mortality data. Infants with DS born in Massachusetts to resident mothers between 1/1/2001 and 12/31/2005 were identified from the MBDMP, which follows cases through age one year. Cases were categorized into four mutually exclusive study groups: DS only, DS+CHD, DS+CHD+OMBD, and DS+OMBD. Children with mosaic and unconfirmed karyotype (n=11) were excluded. Maternal age-adjusted live birth prevalence rates were calculated overall and by study group. CHD and OMBD types were identified using International Classification of Diseases 9th Revision/British Pediatric Association (ICD-9/BPA) codes and CHD were reviewed by clinicians. The distributions of co-occurring defects were calculated, as were the case fatality rates for infants (age <1 year) overall and by study group.

Results: There were 449 live-born infants with DS delivered in Massachusetts from 2001 to 2005, and the maternal age-adjusted prevalence was 9.5 per 10,000 live births. The largest study group was DS+CHD (45.2%), followed by DS only (40.1%), DS+CHD+OMBD (8.2%), and DS+OMBD (6.5%). Over half of all children with DS had a co-occurring CHD with or without an OMBD (53.5%), and 14.7% had a co-occurring OMBD, with or without a CHD. Among infants with CHD, the most frequent type of CHD was septal defects (54.6%), followed by atrioventricular canal (AVC) defects (45.8%), of which over two-thirds were complete AVC. Among infants with DS and at least one OMBD, 22.7% had duodenal atresia, 10.7% had Hirschsprung disease, and 9.1% had an annular pancreas. The overall case fatality rate was 40.1 per 1,000 cases (n=18). Case fatality rates were higher among infants with a co-occurring CHD and/or OMBD compared to those with DS only.

Conclusions: The live birth prevalence of DS in Massachusetts was significantly lower than the national prevalence (13.7 per 10,000 during 1999-2001). Prevalence stratified by maternal age (<35 vs. ≥ 35) was lower in both age groups than stratified estimates from 2000-2004 from 9 states with population-based, active surveillance systems. The co-occurrence of CHD among children with DS was at the high end of the range of several national or state-based estimates (33-56%). Differences may be due to variation in case definitions, defect classification, access to and uptake of prenatal diagnosis and elective termination, and/or population characteristics; or the differences may be real. The development of a standard case-based classification methodology would make regional comparisons more meaningful and would be a useful contribution to birth defects surveillance. This study shows the promise of using a linked, population-based data system to expand and enhance the way surveillance system data can be used to generate a more complete picture of children with DS.

C3.9 Texas A&M HSC IBT/ Texas Birth Defects Epidemiology and Surveillance Branch

Descriptive Epidemiology of Omphalocele in Texas, 1999-2004

A. Agopian, L. Marengo, and L.E. Mitchell

Objective: Omphalocele is a congenital malformation that involves protrusion of abdominal contents into the umbilicus. Though omphalocele is associated with several chromosome abnormalities and genetic syndromes, the etiology for nonsyndromic omphalocele is suspected to be complex, and for most nonsyndromic cases the cause is unknown. The present study sought to ascertain the birth prevalence of omphalocele in offspring of mothers residing in Texas from 1999-2004 and to describe cases' parental and infant demographic characteristics.

Methods: Data on 325 nonsyndromic cases with omphalocele and 2,208,758 live births delivered during 1999-2004 were obtained from the Texas Birth Defects Registry. These data were used to estimate omphalocele birth prevalence and to obtain both crude and adjusted prevalence ratios for the association of omphalocele with parental and infant demographic characteristics.

Results: Omphaloceles were significantly more common in offspring of women without previous live births (adjusted prevalence ratio: 1.80, 95% CI: 1.41-2.30), compared to women with previous live births. Omphaloceles were also significantly more prevalent among offspring of women age 40 and older (adjusted prevalence ratio: 4.83, 95% CI: 2.63-8.86), compared to women age less than 20, and in infants of multiple gestation pregnancies (adjusted prevalence ratio: 2.03, 95% CI: 1.22-3.37), compared to singleton pregnancies.

Conclusions: While previous studies have also found that omphaloceles may be more common among offspring of older mothers and infants of multiple gestation pregnancies, to our knowledge the observed association between omphaloceles and previous live births has not been previously reported. These new findings augment the existing omphalocele literature.

C3.10 Texas Birth Defects Epidemiology and Surveillance Branch

Defect-Specific Survival Experience of Infants with Five Major Congenital Heart Defects

Jason L. Salemi, Wendy N. Nembhard, David A. Fixler, Mark A. Canfield, Mary Ethen

Background: Birth defects are the leading cause of infant morbidity and mortality in the United States and congenital heart defects (CHD) are the most common of all birth defects with an annual prevalence ranging from six to twelve affected infants per 1,000 live births. Infants born with a single functional ventricle have the highest mortality of any CHD, typically requiring 2 complex surgeries in the 1st year, and a 3rd complex procedure in early childhood. Although advances in clinical care, primarily through pediatric cardiology and surgery, have improved outcomes of infants with these types of CHDs, they collectively remain the most fatal of all birth defects. The objective of this study is to examine the defect-specific five-year survival for infants with cardiac lesions with single left or right ventricles.

Methods: We used data from the Texas Birth Defects Monitoring Program to conduct a retrospective cohort study on 1,007 live-born infants with CHDs born between January 1, 1998 and December 31, 2003 to Texas resident women 15-44 years old. CHDs included in the study were d-transposition of the great arteries (TGA), tricuspid valve atresia, pulmonary valve atresia, hypoplastic left heart syndrome (HLHS), and single ventricle. Each case was reviewed by a pediatric cardiologist for confirmation of defect classification. The Kaplan-Meier method was used to calculate 5-year unadjusted survival rates and separate Cox-proportional hazard regression models were used to compute adjusted hazard ratios (HR) and 95% confidence intervals (CI) for each defect. Maternal race/ethnicity and education, era of birth, and presence of extra-cardiac defects were obtained from medical records and included in the models to adjust for potential confounding.

Results: Five-year survival was highest for infants with isolated d-TGA (92.6%; 95% CI: 88.0, 95.5) and tricuspid valve atresia (78.1; 95% CI: 64.7, 86.9). The lowest five-year survival was for infants with hypoplastic left heart syndrome (40.9; 95% CI: 34.9, 46.8) and pulmonary valve atresia (56.6; 95% CI: 45.8, 66.0). After adjusting for potential confounders (race-ethnicity, era of birth, maternal education, and presence of extracardiac defects), infants with hypoplastic left heart syndrome had the poorest survival (HR=9.1; 95% CI: 5.8, 14.2) followed by pulmonary valve atresia (HR=4.8; 95% CI: 2.9, 7.9) and single ventricle (HR=4.5; 95% CI: 2.9, 7.1) compared to infants with d-TGA.

Conclusions: There is significant variability in the five-year survival experiences of infants with certain major CHDs. Other factors associated with childhood survival need to be identified and investigated.

C3.11 Texas Birth Defects Registry

Descriptive Epidemiologic Characteristics of Anencephaly and Spina Bifida by Race/Ethnicity in Texas, 1999-2004

Tasneem Husain, Amy P. Case, Mark Canfield

Objective: A number of investigations have found that the risk for neural tube defects differs between non-Hispanic Whites and Hispanics. To understand why, we compared the descriptive epidemiology of anencephaly and spina bifida for the two race/ethnic groups. Because the Texas Birth Defect Registry (TBDR) has data on 1,879,864 live births, comprises a sizeable Hispanic population, and incorporates all pregnancy outcomes, it permitted detailed comparison of the descriptive epidemiology of anencephaly and spina bifida by race/ethnicity.

Methods: Data on cases with anencephaly and spina bifida among 1999-2004 live births were obtained from the Texas Birth Defects Registry, a population-based active surveillance system. For each descriptive epidemiologic feature, we calculated overall and category-specific prevalence of anencephaly and spina bifida for non-Hispanic Whites and Hispanics. We also calculated crude and adjusted birth prevalence ratios and corresponding 95% confidence intervals between descriptive epidemiologic characteristics and anencephaly and spina bifida for non-Hispanic Whites and Hispanics. Adjusted analyses were limited to those epidemiologic characteristics where the missing data comprised <20% of the total for either non-Hispanic Whites or Hispanics. For anencephaly, we adjusted for infant sex, maternal age, parity, Texas-Mexico border residence, and delivery year. For spina bifida, we adjusted for infant sex, maternal age, maternal education, parity, history of non-live births, Texas-Mexico border residence, and delivery year.

Results: In Texas, for the years 1999-2004, the prevalence of anencephaly among non-Hispanic Whites and Hispanics was 0.96 per 10,000 live births and 1.85 per 10,000 live births, respectively. The prevalence of cases with spina bifida among non-Hispanic Whites and Hispanics was 1.49 per 10,000 live births and 2.41 per 10,000 live births, respectively. Parity expressed a positive linear relationship with anencephaly in both non-Hispanic Whites and Hispanics. Maternal age expressed a significant inverse relationship with anencephaly in both race/ethnic groups. There were two notable differences between non-Hispanic Whites and Hispanics. Infant sex was associated with anencephaly only among non-Hispanic Whites and maternal education was associated with spina bifida only among Hispanics.

Conclusions: Non-Hispanic Whites and Hispanics are similar in their descriptive epidemiology of anencephaly and spina bifida. For anencephaly, both race/ethnic groups express significant trend relationships for maternal age and parity. Both characteristics play a stronger role among non-Hispanic Whites, a difference that warrants further study. The relationship between education and spina bifida found among Hispanics but not non-Hispanic Whites may have ramifications when developing health interventions.

C3.12 Utah Birth Defect Network

Epidemiologic Characteristics of Hypospadias in Utah, 1999-2006

Miland Palmer, Kristen Willey, Sergey Krikov, Marcia L. Feldkamp

Objectives: To evaluate the epidemiologic characteristics, overall and by severity, of hypospadias in Utah from 1999 to 2006.

Methods: Hypospadias cases delivered between 1999 and 2006 among all pregnancy outcomes (i.e., live born, stillborn and pregnancy terminations) were identified by the Utah Birth Defect Network (UBDN), a population-based statewide surveillance system. The overall prevalence of hypospadias and prevalence by maternal age, race/ethnicity, and etiologic classification were calculated. Cases were also analyzed by severity of the hypospadias defect: first degree (coronal margin, glanular, or megameatus with surgical repair); second degree (sub-coronal or shaft); and third degree (penoscrotal or perineal).

Results: From 1999 to 2006 there were 1,206 cases of hypospadias identified by the UBDN. The majority of these cases were first degree, 975 (80.8%), with 176 (14.6%) second degree and 44 (3.6%) third degree, 11 (.9%) were classified as hypospadias not otherwise specified (NOS) due to lack of clinical information. Overall prevalence of hypospadias in Utah was 30.4 per 10,000 births (95% CI: 27.92, 32.75) with an increase observed over the study period (27.5 per 10,000 births in 1999 to 33.7 per 10,000 births in 2006). Prevalence by race/ethnicity and severity of defect is shown in table 1. Using the UBDN etiologic classification schema, 1,104 (91.5%) cases were isolated-pure, 71 (5.9%) were considered multiple (hypospadias with at least one other major birth defect), and 19 (1.6%) were due to a chromosomal or genetic abnormality. The remaining 12 (1.0%) hypospadias cases had either an additional minor birth defect, were part of a sequence, or represented a provisionally unique pattern. Prevalence based on maternal age ranged from 24.6 per 10,000 (less than 20 years of age) to 32.7 per 10,000 (30 to 34 years of age).

Table 1: Hypospadias Prevalence in Utah by Maternal Race/Ethnicity and Severity of Defect.

Race / Ethnicity	1 st Degree	2 nd Degree	Hypospadias 3 rd Degree	NOS	Overall
Non-Hispanic White	24.86	3.99	1.38	3.36	33.58
Non-Hispanic Black	18.08	0.00	3.62	3.62	25.32
Native American	13.68	0.00	3.91	0.00	17.59
Asian	16.59	3.32	2.49	0.83	23.23
Hispanic	6.71	2.00	0.54	0.91	10.16
Other/Unknown	98.00	12.25	8.17	24.50	142.92
Total	22.34	3.66	1.39	3.03	30.42

Conclusions: Utah's hypospadias prevalence is consistent with that reported by the Metropolitan Atlanta Congenital Defects Program (30.85 per 10,000). In Utah, the prevalence of hypospadias was highest among Non-Hispanic Whites and lowest among Hispanics. Though the UBDN has only monitored hypospadias for eight years, prevalence slightly increased during the study period.

Category 4: Prevention, Intervention, and Public Policy- Systematic Evaluation of Prevention Activities and Improving Access to Services, Analysis of Public Policy, Analysis of Public Awareness, Use of Surveillance Data to Measure Outcomes

C4.1 Colorado Responds to Children with Special Needs

Evaluation of a Notification Program for Linking Families to Services

Amy Alman, Russel Rickard

Background: The CRCSN notification program has been referring families with children with special health care needs to local public health agencies since 1989. In November of 2006 the paper-based system was replaced with an electronic system. The electronic system, called the IDS (Integrated Data System), receives text files containing contact and diagnostic information from CRCSN, imports them into a standard format, and distributes them to the Health Care Program for Children with Special Health Care Needs (HCP), and then to the local public health agencies based on residence of the family. The local public health agency then responds to each notification in an application designed to facilitate responses to the notifications and the response is returned to CRCSN in XML format. The IDS provides a seamless electronic data system for receipt, delivery, and response to the notifications. The process also standardized the responses to the notification, reduced paper usage, and increased the efficiency of the program. With the increase in standardization, came the ability to evaluate the response data to develop data-driven strategies for improving the program.

Methods: Using SAS statistical analysis software, response data from November of 2006 through September of 2008 were evaluated. To examine if certain diagnoses result in poorer outcomes to the notification, diagnoses were grouped into diagnostic categories based on the three-digit grouping of the ICD-9-CM code. Appropriate univariate and multivariate statistical analyses were performed to describe the data and examine the responses to the outcomes, appropriately categorize diagnoses, and determine factors that improve the response to the notification. The main outcome evaluated was whether or not the notification resulted in an attempted contact with the family.

Results: During the evaluation period, there were 11,361 notifications sent to HCP via the IDS. Of those, a response had been received on 11,254 (99%) at the time of this evaluation. Overall, 68.66% of notifications result in an attempted contact with the family. The total volume of notifications that the agency received was found to have a statistically significant decreasing trend on the percentage of notifications that result in an attempted contact. The diagnostic category also significantly affects whether or not the notification results in an attempted contact. Genital anomalies result in an attempted contact with the family in just 19.80% of the notifications while chromosomal anomalies result in an attempted contact percentage of 91.48%. In a multivariate logistic regression model, the diagnostic category, the child's age, and the total volume of notifications received by the agency were the most important factors in determining whether the notification resulted in an attempted contact or not.

Conclusions: The total volume of notifications received by the agency and the diagnoses contained in the notification significantly influence whether the notification results in an attempted contact with the family. Public health programs often face limited resources and must make decisions about where to target resources to achieve the greatest benefit. The notification program, as a public health program, is no different. We must make decisions between targeting limited resources and casting a wide safety net to prevent the greatest number of secondary disabilities. Responding to notifications that do not result in an attempted contact with the family is an inefficient use of these limited resources. As such, identifying means to reduce the number of notifications could result in an overall improvement in the notification program.

C4.2 Colorado Responds to Children with Special Needs

2007 Survey of Parents of Children with Down syndrome: Collaboration Between Mile High Down Syndrome Association and Colorado Responds to Children with Special Needs

Amy Alman, Sarah Hartway, Russel Rickard, Margaret F. Ruttenber

Background: In 2007, the birth defects monitoring and surveillance program of the Colorado Department of Public Health and Environment, Colorado Responds to Children with Special Needs (CRCSN) and Mile High Down syndrome Association (MHDSA) joined forces to conduct a parent survey. CRCSN and MHDSA combined efforts to design a survey questionnaire, sent to parents of children with Down syndrome in Colorado, to answer questions about types of prenatal testing parents had selected as well as the parent perspective about prenatal testing options and outcomes. MHDSA had conducted a similar survey in 2004 using their membership database. By joining together, we were able to expand outreach activities for both programs and reach a larger population.

Methods: CRCSN collects data on children who are born to Colorado residents and in whom a congenital anomaly is diagnosed before their third birthday. Diagnostic data are collected passively from multiple sources. CRCSN monitoring procedures require all reports of Down syndrome to go through an active medical record review to eliminate false-positive cases. For this analysis, only cases of Down syndrome in live births confirmed through a medical records review from 2004-2006 were included. MHDSA provided cases from their membership database that included children up to two years of age during the same time period.

The survey collected information on the demographics of the biological parents (index family), what if any type of prenatal screening or diagnostic testing was done, how the parents were told of the child's diagnosis, follow-up health care for the child and overall parent perspective about these processes.

Results: 218 surveys were mailed, 84 families responded for a 38% response rate. 80 respondents were biological mothers, 9 were biological fathers with some surveys completed by both parents together; an adoptive mother completed 1 survey. Mean maternal age at time their child was born with Down syndrome (n = 83), 34.8 with 1 no response. Mean paternal age at time of birth (n = 76), 36.9 with 8 no response. 62% of parents reported that they had some form of prenatal screening for Down syndrome such as quad screen and/or specialized ultrasound. Of these parents, 17% did not realize what they were being tested for until they were given the results. 45% of respondents were encouraged to have diagnostic testing such as amniocentesis; 28% did have diagnostic testing.

Conclusion: The findings that indicate positive changes in 2007 as compared to 2004 include: (1) More parents of children with Down syndrome reported being offered prenatal screening tests as an option, rather than having blood drawn then learning what test was conducted afterward; (2) More parents reported being able to get their questions answered at the time of diagnosis; (3) significantly more parents reported being given this diagnosis in a timely and sensitive manner.

Although CRCSN does not collect any prenatal information on the trisomy 21 cases within the birth defects surveillance system, by collaborating with MHDSA we were able to conduct an analysis of the case data and detect any trends, downward, static, or upward, regarding this health outcome and the families' personal experiences.

C4.3 Michigan Fetal Alcohol Syndrome Prevention Project

Strategies to Prevent Fetal Alcohol Syndrome through Motivational Interviewing

Lisa J. Ficker, Cheryl Lauber, Sandra King, Jewell Akins, Dranoel Knox

Objective: Surveys of women in prenatal care at busy clinics in Detroit have reported 12.5% continue to drink during pregnancy (Flynn et al, 2003) and women in substance abuse treatment programs in Wayne County, which encompasses Detroit, have an incidence rate for FAS of 4 in 1000 births. The goal of the current study was to intervene with women at high risk for an alcohol exposed pregnancy using techniques of Brief Motivational Interviewing (BMI). BMI has demonstrated effectiveness in clinical settings to reduce risky alcohol consumption (Miller & Rollnick, 2002) and has been effectively used in a public health setting to promote HIV risk-reduction practices, such as condom use, among low-income urban women (Belcher et al., 1998).

Methods: The Michigan Fetal Alcohol Syndrome Prevention Project funded by the CDC has found that one third (33%) of 1,784 women screened at the HIV/AIDS-STD clinic and Primary Health Care clinics at the Detroit Department of Health were at risk for an alcohol exposed pregnancy defined as binge drinking (at least 4 drinks per occasion) in the last three months, while they are having sex with inconsistent or no contraception. This intervention utilized Brief Motivational Interviewing (BMI) and developed written materials based on the Project CHOICES intervention model which utilizes BMI to assess readiness for change, provide a dialogue that strengthens the motivation to change, and sets up an individualized change plan. After the initial meeting with a prevention interventionist, three follow-up sessions were provided (one in-person, two via telephone) to continue the Motivational Interviewing and conduct assessment of drinking, sexual frequency, and contraceptive activity. After the participant completes each session of the intervention, she receives an incentive gift that increases in value. A Self-Guided Change version of the intervention was offered for women who wanted to utilize the materials at home and receive two follow-up telephone calls following baseline interview.

Results: Both strategies based on principles of Motivational Interviewing have been shown to be effective in reducing drinking and increasing contraceptive use. The program has enrolled 403 eligible women and 250 have completed the intervention. Of the 75 women enrolled in BMI, 60 women completed the Brief Motivational Interviewing (BMI) intervention. After three follow-ups, 45 (75%) of these women had reduced their risk for an alcohol exposed pregnancy and 38 (63%) of them were no longer at risk, i.e., no binge drinking for 90 days and/or 100% consistent, effective contraception use for 90 days. Of the 326 women enrolled in the Self-Guided Change (SGC) intervention, 190 women completed the intervention. Of these 190 women, 75% were no longer at risk for an alcohol exposed pregnancy, i.e., no binge drinking for 90 days and/or 100% consistent and effective contraception use for 90 days.

Conclusions: Motivational Interviewing is an effective strategy for reducing risk of an alcohol exposed pregnancy among low-income, minority women. Brief Motivational Interviewing in person has less attrition than the Self-Guided Change intervention that utilized Motivational Interviewing in an interactive workbook, but both strategies were equally effective.

C4.4 National Association of County and City Health Officials (NACCHO)

NACCHO Preconception Care Initiative: Support to Rural Local Health Departments

Erin Cox

Objective: The National Association of County and City Health Officials (NACCHO) worked with three local health departments (LHDs) in rural communities through a demonstration site project. The goal of NACCHO's Rural Preconception Care Initiative was to improve the capacity of rural local health departments to address the preconception health and health care needs of individuals in their community through coordination of existing health department and community services. The preconception period represents a critical opportunity for LHDs to intervene. Rural LHDs often deliver many of the components of preconception care, including health education on topics such as family planning, tobacco and substance use during pregnancy, birth defects, domestic violence, sexually transmitted diseases, and HIV. They also provide information to promote exercise, proper nutrition, and the importance of folic acid. With tight budgets and limited resources, there is significant need for the coordinated delivery and promotion of preconception health and health care services. Rural health departments must overcome silos, take inventory of services within the health department, and strategize with community partners to strengthen financial, human, and capital resources for the effective delivery of preconception health services. Promoting preconception care and creating a plan to carry out these interventions provides an opportunity for rural LHDs to integrate and strengthen services.

Methods: Project staff developed a request for applications to identify LHD demonstration sites. Applications were judged by NACCHO's Maternal and Child Health/Birth Defects Prevention Workgroup. Selected demonstration sites were: Hertford County (NC) Public Health Authority Okanogan County (WA) Public Health Uncas (CT) Health District. Demonstration sites received travel stipends to The Second National Summit on Preconception Health and Health Care; a three-day training on coalition development (Coalition University); and ToP® (Technology of Participation) Group Facilitation Methods. The demonstration sites formed coalitions made up of diverse community partners to address poor birth outcomes. Sites also received ongoing peer to peer technical assistance. NACCHO staff conducted site visits to the LHD demonstration sites and observed coalition meetings at each site. During these meetings, LHDs met with community partners to assess the current state of affairs regarding the delivery of preconception care services and birth defects prevention efforts, identified resources and perceived challenges, and discussed ways to overcome challenges and improve birth outcomes in their communities.

Results: The poster will highlight the specific demographic characteristics of each community, as well as the goals and challenges of each LHD demonstration site. (All sites had poor maternal and child health outcomes, including high rates of birth defects and unintended pregnancy, and low rates of folic acid consumption). Successes from the initiative include: education and awareness of reproductive life planning, physician education and training, preconception health messaging to community college students, and partnership with a local tribal organization to create public service announcements. In addition, Uncas Health District was extended the opportunity to speak before the statewide advisory committee on maternal and child health to present data on birth defects prevalence. This allowed them to stress the important needs and challenges of rural regions, particularly related to birth defects. This rural county has the highest prevalence of cardiovascular system birth defects in the state and rates for central nervous system and chromosomal defects are among highest in the state- higher than all urban areas. Demonstration sites were provided with tools, resources and networking opportunities to help them leverage funds to sustain their efforts. All sites have sustained their coalitions by seeking additional funding, from private foundations and the March of Dimes.

Conclusions: Capacity for addressing birth defects prevention through a preconception health framework among three rural LHDs was strengthened. LHDs play a very significant role in birth defects prevention and

preconception health promotion. The LHD served as the lead organization in this process, and brought together diverse community partners which led to three successful local coalitions. NACCHO's demonstration site project increased content knowledge and enhanced skill development among participants. Peer exchange of information and sharing of lessons learned was invaluable. The skills and knowledge gained through the Summit and the trainings enabled demonstration sites to create and sustain beneficial partnerships to address birth defects prevention and poor birth outcomes through a preconception health lens.

C4.5 National Center on Birth Defects and Developmental Disabilities, CDC

Health Care Expenditures for a Privately Insured Population of Infants and Young Children with Congenital Heart Defects, 2005

Sheree L Boulet, Tiffany Riehle-Colarusso, Scott D Grosse, Adolfo Correa

Objective: Congenital heart defects (CHDs) are a diverse group of serious birth defects that impact mortality and morbidity and often require hospitalization and other costly medical treatments. To estimate health care costs for a privately insured population of infants and young children with CHDs, we analyzed health insurance claims data for individuals enrolled in employer-sponsored health plans.

Methods: Data from the 2002-2005 Medstat Marketscan Commercial Claims and Encounters database were used to identify children less than 3 years old with and without congenital heart defects; only medical care expenditures during 2005 were evaluated. Children with CHDs were identified by the presence of an ICD9-CM code of 745.0-747.9 in any inpatient or outpatient claim. We excluded 1) premature infants with isolated atrial septal defects or patent ductus arteriosus (PDA); 2) all CHD cases with isolated pulmonary artery anomalies, isolated PDA, or isolated mitral insufficiency; and 3) CHD cases with selected defects in isolation and without a Current Procedural Terminology (CPT) code related to treatment of CHD. Children with CHD were assigned into one of four mutually exclusive severity categories (isolated severe, multiple severe, isolated mild, multiple mild). Analysis was restricted to children who were enrolled in a fee-for-service plan in 2005 and for whom data on pharmaceutical claims were available. Children ages 1-2 years were included only if they were continuously enrolled in 2005; all infants (<1 year of age) were included due to high mortality rates during the first year of life. Average and median costs and cost ratios for inpatient, outpatient, and prescription drug claims were calculated for children with and without CHDs.

Results: For children 1 to 2 years of age with CHD, mean medical care costs were 9 to 12 times greater than for children without CHD; median costs were 4 times greater. The difference in mean costs between those with CHD and those without CHD was \$26,766 for 1-year-olds and \$12,186 for 2-year-olds. Mean and median costs for infants with CHDs were 25 and 15 times greater, respectively, than costs for infants without CHDs, and the difference in mean costs was \$94,050. Mean costs were 2-3 times higher for infants and children with multiple severe CHDs than for those with isolated severe defects and 5 to 15 times higher than for those with isolated mild defects.

Conclusions: These findings suggest that medical expenditures for children less than 3 years of age with CHD are substantially greater than those for children without CHD, with greatest disparities noted among infants < 1 year of age. Understanding the costs for medical care for children in privately and publicly insured populations can contribute to an understanding of the potential benefits of interventions to prevent CHD.

C4.6 National Center on Birth Defects and Developmental Disabilities, CDC

Preventing Infections During Pregnancy: Testing Combined Prevention Messages and Exploring Women's Preferences Related to the Format and Visuals of Educational Materials

Katie Kilker Green, Christine E. Prue, Sonja A. Rasmussen, Angela Colson, Abigail Tumpey, Bruce Brown

Objective: The objectives of this study were to test prevention messages related to infections during pregnancy for clarity and appropriateness and to explore preferences related to the written delivery of those prevention messages, combined in one educational material, among English- and Spanish-speaking women of childbearing age.

Methods: Researchers conducted six, two-hour focus groups (three in English and three in Spanish) with women 18 to 35 years of age who were currently pregnant, were planning pregnancy, or had a baby in the last four years. Each focus group explored a different aspect of the written educational material. The first group was asked only about content of a simple, one-sided, standard letter sized fact sheet, which included a comprehensive set of messages aimed at preventing infections during pregnancy. The second group was asked only about preferred format; participants were shown the same prevention messages in four different formats: a tri-fold brochure, a wall poster (18" x 22"), a web page, and a one-sided fact sheet (standard letter size). Finally, participants in the third group were asked about the visual appeal of the previously tested formats and graphical elements (photos, colors, font, etc.).

Results: Many concrete recommendations for improvement were gleaned from each group. Results from the content groups suggested that although the women had clear understanding of the prevention messages, they expressed a desire for more information about specific consequences of contracting different infections during pregnancy. Also, the women suggested that heightening focus on infection prevention tips that are less commonly known (i.e. avoidance of non-pasteurized cheeses, reheating deli-meat, not sharing food/utensils with young children, risks from pets, Group B Strep testing, etc.) would better capture their attention than leading with tips that are widely known (i.e. handwashing, etc.). The participants in the format groups overwhelmingly preferred a tri-fold brochure format to other options, yet suggested that pairing a brochure along with a wall poster might be most successful in getting their attention and drawing them in. And finally, the participants who were asked to focus on visual appeal suggested modifying the selection of images so that photographs used better reflected the culture and ethnicity of the intended audience and so that other accompanying images were more illustrative of the actions that the reader is being asked to do. Overall, there were very few differences between the responses and suggestions from English- and Spanish-speaking participants.

Conclusions: Message testing is an essential step in the development of effective educational materials that helps to ensure that a final product is appropriate for, understood and accepted by the intended audience. This message testing experience and the exploration of women's preferences related to written information about preventing infections during pregnancy has confirmed the aspects of message and materials development that were done well, while also uncovering many important areas for improvement that is needed to capture and maintain our audience's attention.

C4.7 National Center on Birth Defects and Developmental Disabilities, CDC

Knowledge and Attitudes of Women of Reproductive Age Towards Smoking and Adverse Pregnancy Outcomes: Results from the 2008 HealthStyles Survey

Paramjit Sandhu, Kara N. Duwe, Margaret A. Honein, Katie Kilker, Judith Berkowitz, Lucinda England, Sonja A. Rasmussen

Objective: Smoking during pregnancy is a risk factor for certain birth defects and other adverse pregnancy outcomes. To guide development of future messages aimed at decreasing the rate of smoking during pregnancy, we sought to examine knowledge and attitudes of adults in the United States towards smoking during pregnancy and its effects on pregnancy and infant outcomes.

Methods: For this analysis, we used data from the Porter Novelli HealthStyles survey, a postal mail survey conducted in the United States since 1995. In 2008, questions were added to assess knowledge about adverse effects of smoking on pregnancy and infant outcomes, factors that would persuade women of reproductive age who smoke to quit smoking during pregnancy, and knowledge about the potential benefits of smoking cessation during pregnancy. A total of 7,000 surveys were mailed and 5,399 responses were received, yielding a 77.1% response rate. Among the respondents were 2,408 men, 2,991 women, and 1,053 women of reproductive age (18-44 years). The data were weighted by matching age, sex, race/ethnicity, income, and household size variables to annual U.S. census data, resulting in a weighted sample of 1,437 reproductive-aged women. We calculated descriptive statistics to examine knowledge about smoking during pregnancy by demographic and lifestyle factors.

Results: Knowledge about adverse effects of smoking during pregnancy was higher among women of reproductive age than among the general population, with 39% of reproductive-aged women answering at least 5 out of 6 questions correctly, compared to 27% of the general population ($p < 0.000001$). Factors negatively associated with knowledge in the general population included lower education, older age, white and black race-ethnicity (compared to Hispanic), and smaller household size. Most women of reproductive age who smoked (~70%) reported that they would consider quitting smoking if their health care provider recommended that they do so, even if the provider didn't provide a specific reason. Over 80% of all respondents and 88% of reproductive-aged women agreed that a woman who smokes should quit smoking before becoming pregnant, but most did not recognize the value of smoking cessation later in pregnancy.

Conclusions: In the United States, many women continue to smoke during pregnancy despite the recognized adverse effects on the pregnancy and fetus. Our findings suggest that additional efforts toward educating the general population and women of reproductive age on the effects of smoking during pregnancy are needed. Additional research is needed to better understand the knowledge and attitudes towards smoking during pregnancy to guide future interventions aimed at smoking cessation before and during pregnancy.

C4.8 National Foundation for Facial Reconstruction

Use of Formative Evaluation by a Community-Nonprofit-Provider Partnership to Develop Educational Materials for Parents of Children with Craniofacial Conditions

Marcie S. Rubin, Dennis Sklenar, Elsa Reich, Aileen Blitz, Whitney Burnett

Background: Parents of children with craniofacial conditions often lack important information needed to make informed health care decisions. To address gaps in knowledge and expand consumer health literacy, a community-nonprofit-provider partnership used formative evaluation to guide the development of educational materials for parents of children with craniofacial conditions prior to widespread dissemination. Educational guides were developed on the following topics: 1) fostering self-esteem in children with craniofacial conditions, 2) parenting children with craniofacial conditions, 3) genetic testing and counseling, and 4) accessing available resources for children with craniofacial conditions.

Methods: A multidisciplinary group of clinicians with professional experience working at craniofacial centers drafted learning objectives and detailed outlines for the educational guides based on clinical expertise and previous encounters with parents of children with craniofacial conditions. These materials were shared with two samples of mothers of children with craniofacial conditions (N=14) receiving care at either a craniofacial institute in New York or Michigan who were diverse with respect to race/ethnicity, nativity, and child's age, gender, and craniofacial conditions. Structured telephone qualitative interviews with mothers were utilized to assess the extent to which the draft guides were comprehensive, informative, clear, and useful for parents. Using an iterative process, the initial templates were revised into educational guides, peer reviewed by clinicians previously unexposed to the materials, further modified, and copy edited. Next, experts from the Centers for Disease Control and Prevention reviewed the guides and semi-structured telephone interviews were conducted with the parent sample (N=12). Findings from each of these evaluation activities were triangulated and utilized to refine the educational guides to ensure that the materials were comprehensive, informative, clear, readable, and helpful to parents. The final guide text was graphically laid out and prepared for publication and dissemination.

Results: This project generated multiple direct and indirect outcomes. First, comprehensive, tailored educational guides on self-esteem, parenting, genetic counseling, and resources were developed for parents of children with craniofacial conditions. Findings from evaluation activities suggest that providers will embrace the materials and end users will find them to be informative and helpful. Second, the use of a partnership model with professional and community input was found to be effective in developing health education materials that encapsulated pertinent clinical information in a format that was meaningful and comprehensible to parents of children with craniofacial conditions. Third, a nonprofit organization, the National Foundation for Facial Reconstruction, was successfully able to function as a bridge between providers and families. Finally, interdependent partnerships among community members, a nonprofit organization, and providers were established and will serve as a foundation for future collaborative projects.

Conclusions: A community-nonprofit-provider partnership can be instrumental in informing the development of health education materials. The use of formative evaluation is an effective strategy to guide the creation and evaluation of educational guides on health care topics relevant to parents of children with special needs.

C4.9 North Carolina Folic Acid Campaign/March of Dimes

Two-Years Later: How Multivitamins, Folic Acid and Birth Defect Knowledge and Behaviors Changed among Hispanic Women in North Carolina After a Multi-Faceted Intervention

Leslie deRosset

Objective: The consumption of folic acid prior to conception can prevent up to 70% of neural tube defect (NTD)-affected pregnancies, but state and national research indicates that Hispanic women are less likely to consume a daily multivitamin than other racial/ethnic groups. In North Carolina, between 1995/1996 and 2004/2005, the overall NTD prevalence decreased approximately 40% and nearly 43% for Hispanics; however, the Hispanic prevalence was still almost double that of other races/ethnicities. To evaluate the effectiveness of a multi-faceted educational campaign, the researchers used a quasi-experimental design to measure the knowledge, beliefs and behaviors of Spanish-speaking Hispanic women ages 18 to 35 in regards to multivitamins, folic acid, and birth defects.

Methods: Using probability proportional to the combined size of the pair, six pairs of counties were randomly selected for participation (6 urban and 6 rural), resulting in a total of 12 selected counties. From each pair, one county was randomly assigned to the intervention and the other served as the comparison. Baseline surveys were administered in the 12 participating counties in 2006, followed by the implementation of a multi-faceted educational campaign in the intervention counties (health care provider education, a lay health education program and a paid media campaign). The comparison counties received only a paid media campaign. In 2008, posttest surveys were collected in all 12 counties. Data were weighted and analyses were conducted using SUDAAN.

Results: Total respondents in 2006 (N = 896) were significantly less likely to be knowledgeable about multivitamins and folic acid compared to total respondents in 2008 (N = 1,145). In 2008, Hispanic women in comparison counties were significantly less likely to be knowledgeable about multivitamins compared to those in intervention counties, however multivitamin consumption in comparison counties was significantly higher than in the intervention counties. Significant predictors of daily multivitamin use included: educational attainment of high school or greater and a previous pregnancy. Factors that significantly predicted knowledge of multivitamins, folic acid and birth defects were: emigration from an urban area in the country of origin, educational attainment of middle school or greater, and having lived in the United States between six and 10 years. Folic acid knowledge was also significantly predicted by reporting a previous pregnancy. Finally, having been pregnant and residing in an intervention county also significantly predicted multivitamin knowledge. Women in comparison counties were significantly less likely to report having received information from health care providers, family/friends or health centers compared to those in intervention counties.

Conclusions: This study indicates that the multi-faceted campaign effectively increased knowledge, but this increase in knowledge did not translate to vitamin-taking behavior changes. On the contrary, the media only campaign appears to have been more effective at changing behavior. A longer intervention period may have altered the study results, and further study is needed to better understand the complex relationship between knowledge acquisition, behavior change and the most effective mechanisms for impacting both knowledge and behavior of Hispanic women.

C4.10 Oklahoma Birth Defects Registry

Results of a Needs Assessment Survey of Children Born with Birth Defects in Oklahoma

Kay Pearson, Elizabeth Jean Kidd

Objective: The Oklahoma Birth Defects Registry (OBDR) mailed a questionnaire to the families of children with birth defects to ascertain health care needs and barriers to care encountered from the preconception throughout childhood. The SLAITS (State and Local Area Integrated Telephone Survey) was used as a guide for the development of a questionnaire, which was shared with and revised by an advisory committee. Sixteen focus groups of parents of children with birth defects were conducted around Oklahoma. The parents provided invaluable suggestions for revision of the cover letter and questionnaire that was mailed to 1,030 families. We received responses from 155 families and 149 questionnaires were returned undeliverable.

Methods: The survey, containing 60 separate questions, was analyzed by dividing the questions into six sections: preconception counseling, diagnosis of defect, health care services, payment for health care services, transportation and impact of birth defect(s) on the family. Analysis consisted of percentage of Yes/No responses to questions.

Results: Due to the number of questions, only a highlight of responses is discussed. Pre-pregnancy education was received by 33 percent of the women. Fifty-seven percent were told to take a multivitamin before pregnancy. Of those that were told, 85% reported taking a multivitamin. The majority of children (83%) were diagnosed during the prenatal period or at birth. Almost one-fourth of parents (24%) had questions related to their child's birth defects diagnosis that were unanswered. The top three services utilized by families were: 63% dental care, 45% speech therapy and 39% physical therapy. Eight-two percent of families were satisfied with the services provided, with 87% of the children seeing a specialist in the past year. The majority of families (64%) pay for health services through Medicaid, while 42% have private insurance and 14 % utilize self-pay. Greater than one-third of families report their child has or will have medical expenses that are not paid for by an outside source. Only 7% reported problems keeping appointments due to transportation. While 40% of families drive greater than 50 miles to their primary care physician, 67% drive greater than 50 miles to a specialty clinic. Almost 60% of respondents reported a family member stopped working at some point to stay home with their child.

Conclusions: The response rate of approximately 18% highlights the difficulty getting families to return surveys. The need for preconception care is obvious. The majority of families are satisfied with the health care services their child receives, but financial issues continue to plague families throughout their child's life. Given the rural nature of Oklahoma and the distance families have to travel for services, it was amazing that transportation did not appear to be a barrier to care for families. There appears to be a need for additional education at the time of their child's diagnosis. While not discussed, families with private insurance reported more difficulty paying for medical care and services than families receiving Medicaid.

C4.11 Puerto Rico Birth Defects Surveillance System

Pilot Evaluation of the Satisfaction with Services of Families Referred to the Children with Special Health Care Needs Pediatric Centers by the PR Birth Defects Surveillance System

Diana Valencia, Laureane Alvelo-Maldonado, Miguel Valencia-Prado

Objective: A referral protocol for children identified with birth defects by the Puerto Rico Birth Defects Surveillance System (BDSS) to the Children with Special Health Care Needs (CSHCN) pediatric centers was designed by the BDSS staff in 2005. The BDSS referral protocol was implemented island wide at the end of 2006. Families are referred by the BDSS abstractors to one of the seven CSHCN pediatric centers. A pilot evaluation was conducted in 2008 to determine: 1) How many of the identified children are being referred to the CSHCN pediatric centers? 2) Are they reaching the CSHCN pediatric centers? 3) Are they satisfied with the services they get? 4) Do we need to add other health services providers to our community resources list?

Methods: For this pilot evaluation, a sample with replacement (n=50) was selected from the 136 children referred by the BDSS in 2007. Once the families were contacted, they were asked if they actually went to the CSHCN pediatric center or decided to go to other provider. A survey was conducted via telephone with all parents (n= 26) that went and received services at the CSHCN pediatric center.

Results: A total of 21% of 2007 BDSS cases were referred by the BDSS abstractors to the CSHCN pediatric centers. From the 50 families contacted; 52% (26) attended the CSHCN pediatric centers and the interview proceeded. Of the parents that attended the clinic, 88.2% were satisfied with the services; 70.6% reported obtaining appointments on time; 62.0% found the clinic office hours to be sufficiently flexible, and 26.0% did not have to wait too long in the waiting room. Parents felt that areas that could be improved included: receiving verbal and written information about the child's condition, receiving information and guidance for the prevention of future problems and how to locate services for the special needs of their child, and arranging contacts with parents with similar concerns.

Conclusions: Most children with birth defects are not being referred because they are not eligible by the CSHCN Program criteria to receive services at the CSHCN pediatrics centers or the specialties services are not available through these centers. Therefore, in order for the abstractors to refer all children with birth defects born alive to adequate services, the BDSS staff needs to include other health services providers and specialists to the community resources list. Most of the parents interviewed were satisfied with the CSHCN centers services. However, these results also show that there is a need for improving the provision of verbal and written information about the child's condition, prevention of future problems, and other available services by CSHCN clinics professionals. There is also a need for arranging contacts with parents with similar concerns.

C4.12 Rhode Island Birth Defects Program

At-Risk Newborns with Birth Defects by Body System and Program Enrollment in Rhode Island, 2002-2007

William Arias and Sam Viner-Brown

Objective: Rhode Island's Newborn Developmental Risk Screening Program (NRDS) screens every baby born in the state for developmental risk factors based on medical, demographic and psychosocial characteristics. Families of babies determined to be at risk are offered home visits to assure appropriate services and referrals are provided. Although Rhode Island birth defects cases have been associated with demographical risk markers, follow-up of service program enrollment among screened risk-positive newborns in Rhode Island with a birth defect has not been further investigated. The purpose of this study is to examine program enrollment among at-risk newborns with birth defects by body systems.

Methods: Birth defects cases in Rhode Island were collected from 2002 to 2007. A birth defect in Rhode Island includes any ICD-9 diagnosis code in the range of 740-759. Birth defects were generally grouped by body system. A risk-positive result for a birth defects case was defined as a child who was at risk based on NRDS screening criteria of medical, demographic and psychosocial risk factors. Proportions of risk-positive status were compared among body systems for significance. Newborns that represent these higher at-risk groups were followed up for home visit and early intervention services received.

Results: Birth defects related to the chromosomal, orofacial, cardiovascular, and nervous systems had higher proportions (88-93%) for risk-positive status compared to other body systems (71-75%). The majority of babies with chromosomal (90%) and nervous system (86%) birth defects received at least one home visit. Eight-two percent of newborns with chromosomal defects and 75% of newborns with nervous system defects have enrolled in the Early Intervention Program. In addition, a high proportion of children (85%) with orofacial defects (cleft lip/cleft palate) and cardiovascular defects (82%) received home visits.

Conclusions: Children with birth defects related to the chromosomal, orofacial, cardiovascular, and nervous systems are more likely to be screened as risk positive for developmental issues. Children with nervous system and chromosomal defects are more likely to receive social services such as early intervention and home visiting. It is important for birth defects programs to be able to identify at-risk newborns and assure they are linked to appropriate services, such as home visiting and early intervention.

C4.13 Spina Bifida Association (SBA)

Turning Data into Advocacy

Adriane K. Griffen

Objective: The Spina Bifida Association developed the Prevention Program in 2008 as a template for local chapter use on a state and regional level. The program features two presentations: one for business settings and one for school settings. Each presentation features customizable sections that allow the SBA chapter to tailor the information with the SBA-produced State Rate Fact Sheet for that chapter service region. The State Rate Fact Sheets feature state and regional specific information for women of childbearing age, the Hispanic population, rates of Spina Bifida, and the connection between Spina Bifida and folic acid. The State Rate Fact Sheets are an integral component of the Prevention Program and are developed based on data published in the Birth Defects Research (Part A): Clinical and Molecular Teratology, as well as Census data. The goal of the Prevention Program is to reach women of childbearing age with information on folic acid while increasing the public awareness of Spina Bifida.

Methods: SBA developed the Prevention Program and its components in collaboration with local chapters in 2007. The State Rate Fact Sheets were developed in collaboration with the NTD/Folic Acid committee of the National Birth Defects Prevention Network. All materials were tested during in depth interviews with chapter leadership. A total of 6 chapter leaders were interviewed. The following materials for the Prevention Program were developed in 2008 and made available electronically to SBA Chapters online at Leaders Online, SBA's intranet:

- Awareness Presentation
 - Education version
 - Business version
- Presentation User Guide
- Awareness Tips
- Presentation Pretest
- Presentation Post test
- Presentation Completion Certificate

The following take away items are available as companion pieces to the Prevention Program:

- Centrum Coupons co-branded with the Spina Bifida Association
- Folic Acid Every Day brochures (available in English and Spanish)
- What is Spina Bifida? brochures (available in English and Spanish)
- The Cost of Spina Bifida brochure insert (available in English)
- Plan Ahead brochure insert (available in English and Spanish)
- State Rate Facts fact sheet (available electronically)

The Prevention Program also features a built-in evaluation tool for SBA Chapters to assess their progress as well as media advocacy materials for using the State Rate Fact Sheets in local outreach efforts. Three small group trainings have been conducted with SBA Chapters (n=7). Additional large group training will take place in June 2009.

Results: A process evaluation of the Prevention Program was conducted in May 2008. Eight SBA Chapters reported using all of the components of the Prevention Program (33%). As assessed in SBA's National Survey of the Spina Bifida Community, of the women who take folic acid, 36% indicated that they consume daily recommended amount of 400 mcg of folic acid. This is a similar finding from the last national survey.

About 48% of women at increased risk of having a baby with Spina Bifida knew that they need 4000 mcg to reduce the risk of recurrence. This a significant increase - up 5% from the last national survey.

Conclusions: Continued folic acid and Spina Bifida awareness efforts are warranted. SBA needs to continue training local chapters on how to use the Prevention Program and the companion materials in an effort to outreach to more women of childbearing age, while increasing the awareness of Spina Bifida. Additional SBA Chapter trainings are planned for June 2009.

C4.14 Texas Birth Defects Epidemiology and Surveillance Branch

Developing a State-Specific Cost-of-Illness Estimate for Spina Bifida

Amy Case and Mark A. Canfield

Background: Calls to action aimed at adoption of public health policy changes or interventions are often accompanied by various measures of economic efficiency. Put simply, interventions cost money to enact and policy changes often incur or redistribute costs for government entities, individuals, industries and others. Thus it is often necessary to demonstrate a net economic gain in order to mobilize political will and resources needed to make these changes. Several tools are available for identifying the most efficient use of resources in treating and preventing disease, but some methods can only elucidate costs to an entire system (“society”) and do not identify who pays for what and which particular aspect of society (i.e. the individual, hospital corporations, employers, and/or state, local, or federal government agencies) will reap the benefits. This missing information has serious implications for health policy.

One method for describing the economic impact of a disease is the cost-of-illness estimate, which aggregates actual data about direct and indirect services such as medical and rehabilitative care as well as indirect measures such as lost productivity due to disability. This method has the advantage of identifying the source of various associated costs so that the relative burden between different segments of society can be quantified. The distribution of this burden may vary greatly from state to state and these stakeholders may have differing perspectives on which interventions or policies should be enacted, and who should bear the burden of investing in them.

The objectives of this study are to 1) obtain a state-specific cost of illness (COI) estimate for spina bifida by applying existing estimates generated elsewhere to state prevalence data, and 2) to identify and compile other state-specific cost data which could be used to inform policy makers and programs considering prevention initiatives.

Policy makers and other stakeholders are especially interested in cost-of-illness estimates for spina bifida because highly effective, relatively low-cost and low-risk interventions have been identified that could greatly reduce the incidence of this condition (i.e. folic acid supplementation and fortification).

Methods: To generate a simple estimate of the additional annual societal costs of spina bifida for the state of Texas, our calculation used a straightforward model proposed by Waitzman, Romano and Grosse: $TC = \sum_j AVG_j \times N_j$, where AVG is the average cost per case for N number of affected individuals in each jth stratification of interest.

Since distinct entities bear the cost of these policies and prevention programs, it was determined that a more useful tool would be a summary of the actual costs associated with spina bifida for these entities. To develop this, in some cases published data for the U.S. or for other states was applied to Texas rates. In others, direct cost data were available for spina bifida (or related conditions) from various Texas or national data sets. Data were obtained by submitting data requests to the appropriate programs, such as the Purchased Health Unit of the Texas Department of State Health Services.

Results: Waitzman’s recent estimate of average lifetime costs for spina bifida is \$635,000. Based on this estimate, the annual additional cost of spina bifida to Texas would be 136 (average number of spina bifida cases 1999-2004) x 0.87 (% liveborn) x \$635,000, or \$74,930,000. That is, each year another \$75 million in lifetime costs is incurred by the Texas economy due to new cases of spina bifida.

Program or agency-specific data were obtained from several Texas sources. For example, annual costs of treating spina bifida in Texas include \$1.75 million paid by the Title V-funded Children with Special Health Care Needs program; \$6 million is paid through Medicaid/CHIP insurance, and private insurers assume a burden of about \$5.7 million.

Conclusions: While a societal COI can be estimated, it may not be adequate to motivate state- and agency-level spending on interventions. Since most interventions are done at the agency or program level, simple reporting of costs for a particular program may be adequate and will vary by proposed prevention strategy.

While data availability will vary, state birth defect programs can and should develop relationships with health care financing programs in order to compile cost figures for preventable birth defects. Accessible, specific, and current cost data should be compiled to inform and motivate potential prevention partners and policy makers about the economic benefits of birth defects prevention.

C4.15 Vermont Birth Information Network

Designing an Effective Public Education Campaign for Younger, Low Income Women

Peggy Brozicevic and John Burley

Objective: The Vermont Behavioral Risk Factor Surveillance System (BRFSS) survey data showed a significant decrease between 2004 and 2006 in the percentage of women who take a daily folic acid supplement. A similar, but nonsignificant, decrease was found in the percent of women who knew about the role of folic acid in preventing birth defects. Women under 25, with a high school education or less, and annual household income less than \$25,000 were the least likely group to take folic acid on a daily basis. This is also the group that is most likely to have an unplanned pregnancy.

The objective was to identify potential barriers to taking multivitamins amongst young, low income Vermont women, and to design a public health message that addressed these barriers.

Methods: The Health Department contracted with a social marketing firm¹ which conducted two focus groups with young, low-income women. One focus group was conducted in the city with the largest and most diverse population, while the second was conducted in a rural area. In each group perceptions towards multivitamins and health were explored, and potential barriers and encouragements to healthy behaviors were identified.

Results: The women in both groups were very similar. These women had already experienced hardships in their lives resulting in loss of confidence and low self-esteem. They are often in environments where those around them do not support healthy habits. These young women are seeking encouragement and need to feel a sense of accomplishment. A positive role model and supportive environment were identified as key factors to adopting new health practices such as regularly taking multivitamins. The most appealing picture of a role model was found to be a warm and gentle middle aged woman, such as an aunt, who is happy, healthy and active. They could relate better to someone approachable and realistic, rather than a celebrity. Many of the young women seemed to distrust doctors, believing that their focus is primarily on prescribing medication or on making money.

The women were generally aware that multivitamins could be beneficial, but most reported taking them only for short periods when they felt sick or run down. There was confusion about the relative value and effectiveness of different brands of multivitamins, and most viewed multivitamins as expensive.

Conclusions: There were no differences between the women in the two focus groups. These women would respond best to health messages from an appealing, middle aged, female role model. They would like encouragement and support to take small, simple and credible steps towards establishing better health habits. Guidance on how to choose low-cost, high quality multivitamins would be viewed as helpful.

¹ Spike Advertising, Burlington, Vermont and Fifth Element Associates, Colchester, Vermont

C4.16 Wisconsin Birth Defect Prevention and Surveillance Program and Wisconsin Women Infants and Children Program (WIC)

Development of a Birth Defects Nutrition Consultant Network Utilizing an Integrative Model for Nutrition Services Capacity Building through Local WIC Programs

Peggy Helm-Quest, Sherrie Sondel, Mary Marcus, Sue Murvich

Background Nationally, every WIC project has a Nutritionist who is a Registered Dietitian and is committed to assuring that high-risk families receive appropriate nutritional support including; medical nutritional products, nutritional consultation to improve health status and prevent nutrition complications, and family education to assure efforts to nurture their child. This begins with early identification of nutrition-concerns and is supported by referrals and care coordination.

However, it was found in Wisconsin that the number one training need identified by WIC agencies through a Public Health Needs Assessment was serving infants and children with birth defects and related health needs, as WIC Nutritionist's have limited education and training regarding nutritional issues affecting children with birth defects. Thus, when a WIC participant is at high nutritional risk due to or complicated by a birth defect (i.e. failure to grow, formula or food intolerance/allergy, inability to consume breast milk, formula or foods; dysfunctional feeding skills or behaviors) severe nutritional complications, multiple hospitalizations, or death may occur. The Birth Defects Nutrition Consultant Network concept developed out of this need.

Methods Nine WIC projects were identified to participate in this program improvement initiative to develop an integrative model for building local nutrition services capacity and systems development for the identification, intervention and referral of infants and children with birth defects and other health care needs. Between March 06 and Sept. 06, 3,698 infants and 3,438 children were identified WIC participants with birth defects or other health care needs to become the baseline data for this project and to acknowledge that WIC had the ability through their data system to provide identifying data. Beginning in October 2006 and continuing, the State CSHCN Nutrition Consultant and the UW Pediatric Pulmonary Center Co-Director provided weekly 1 hour training and technical assistance to the nine projects via teleconference.

Results: The Birth Defect Nutrition Consultant Network developed a system that addresses:

1. Facilitation of referrals to other services including primary care, tertiary care, Birth-Three, economic assistance, and to local dietitians providing medical nutritional therapy.
2. Communication with families, health care providers, and Birth-to Three agencies.
3. Facilitation of the provision of special infant and pediatric formulas through WIC.
4. Collaboration with family, health care and pharmacists to ensure documentation for Medicaid reimbursement of nutritional products.
5. Training including the development of a Toolkit and Workbook, and a Birth Defect Nutrition Consultant mentorship program to spread to other local WIC projects.

Conclusions: WIC Nutritionist's may be the first to identify the need for assessment and diagnosis referral for a suspected health care need; if a participant's diagnoses warrants additional nutritional assessment and medical nutritional therapy; if a special formula is needed or changed based on diagnosis or no longer needed; or if the quantity needed can not be met by WIC alone. As such, WIC projects are an unrecognized and valuable local resource for identification, intervention and referral for the provision of nutrition services supporting children with Birth Defects and other health conditions.

C4.17 West Virginia CARESS

Distribution of Multivitamins at Family Planning Clinics, Folic Acid Knowledge, and NTD Rates

Melissa A. Baker

Background: The West Virginia Congenital Abnormalities Registry, Education and Surveillance System (CARESS) is a passive birth defects surveillance system that collects data from birthing facilities within the state to study the rates and trends of birth defects, including neural tube defects. The WV Family Planning Program (FPP) contracts with approximately 148 county health departments, primary care and rural health centers, college and university student health clinics, hospitals, and private medical practices to deliver clinical family planning services to eligible individuals. To help in the reduction of NTDs and promote the benefits of folic acid, the FPP began distributing multivitamins with folic acid to clients in 1999. The WV Pregnancy Risk Assessment Monitoring System (PRAMS) is a population based survey of postpartum women and includes questions on folic acid awareness and knowledge. This study illustrates West Virginia's collaborative approach to NTD prevention and describes current trends in NTD prevalence, multivitamin distribution and folic acid awareness.

Methods: Data for 2000-2006 from CARESS, FPP and PRAMS were used for this study. Birth defects surveillance data were used for NTD prevalence. The frequency of multivitamin distribution was assessed using FPP data. PRAMS data were used to evaluate trends in folic acid knowledge.

Results: The number of NTDs reported has declined from a high of 18 in 2000, (a rate of 8.6 per 10,000) to a low of 4 in 2006 (a rate of 1.9 per 10,000). The number of bottles of multivitamins distributed has steadily increased since distribution began. During this time period the percentage of women reporting knowledge of folic acid and its benefit in preventing birth defects has not significantly changed.

Conclusions: Although the percentage of women reporting acknowledging the benefits of folic acid has been relatively unchanged, the number of NTDs has declined. This decrease may be attributed to the multivitamin distribution program, temporal changes in eating habits, or other factors not considered in this study. Currently, health education and counseling regarding the benefits of taking folic acid before becoming pregnant are discussed at family planning clinics. Educational campaigns and public health fairs throughout the state are used to enhance awareness of NTDs and potential risk factors. Multivitamins will continue to be distributed to clients at family planning clinics since the cost of preventive measures is so little compared to the cost of treatment of a child born with an NTD.