Poster Abstracts

Category 1: Case Ascertainment – Innovative Approaches, Use of Physician Office Data, Prenatal Surveillance, Pediatric Cardiac Registries; Environmental Data

C1.1. Title: Hospital Staff Training and the Impact on Passive Reporting of Birth Defects and Other Adverse Pregnancy Outcomes **Program:** Illinois Adverse Pregnancy Outcome Reporting System (APORS)

Program: Illinois Adverse Pregnancy Outcome Reporting System (APO) **Authors:** Carole Strainis, Jane E. Fornoff

C1.2. Title: Supplemental Approaches to Case Ascertainment in Massachusetts I: Ascertainment of Cardiovascular Malformations from Outpatient Cardiology Clinics **Program:** Massachusetts Center for Birth Defects Research and Prevention Massachusetts Birth Defects Monitoring Program (MBDMP) **Authors:** Angela Lin, Elizabeth Bingay, Cathleen Higgins, Sudha Karamuri, Marlene Anderka

C1.3. Title: Supplemental Approaches to Case Ascertainment in Massachusetts II: Targeting Ascertainment Activities: Finding MA Birth Defect Cases in Rhode Island **Program:** Massachusetts Center for Birth Defects Research and Prevention Massachusetts Birth Defects Monitoring Program (MBDMP) **Authors:** Cathleen Higgins, Joseph Burgio, Linda Casey, Marlene Anderka

C1.4. Title: Supplemental Approaches to Case Ascertainment in Massachusetts III:
Faster Ascertainment by Faxing Queries to Physicians
Program: Massachusetts Center for Birth Defects Research and Prevention
Massachusetts Birth Defects Monitoring Program (MBDMP)
Authors: Joseph Burgio, Angela Lin, Cathleen Higgins, Susan Winship, Linda Casey, Marlene Anderka

C1.5. Title: Geographic Information System Analysis of the Association Between Environmental Quality and Neural Tube Defects in OklahomaProgram: Oklahoma Birth Defects RegistryAuthors: Kay Pearson, Rosina Everitte

C1.6. Title: Medical Records vs. Interview Responses: A Comparative Analysis of Selected Variables for Linked Birth Defect CasesPrograms: Texas Center for Birth Defects Research and PreventionAuthors: Mark A. Canfield, Tunu Ramadhani, D. Kim Waller, Amy P. Case

C1.7. Title: Congenital Heart Defect Prevalence and Reporting in Utah, 1999-2002 **Program:** Utah Birth Defect Network **Authors:** Marcia Feldkamp, Luciana Young, Lynne MacLeod, John C. Carey

Category 2: Birth Defects Rates and Trends – Graphical Presentation of Data, Statistical Assessment, Cluster Evaluations

C2.1. Title: A method of Weighted Proportion of Reproductive-Aged Women Taking Folic Acid Supplements to Predict Neural Tube Defects Rate DeclineProgram: National Center on Birth Defects and Developmental Disabilities (CDC)Authors: Quanhe Yang, Michael Atkinson, J. David Erickson

C2.2. Title: Prevalence of Maternal Diabetes in Metro Atlanta, 1968-2000Program: National Center on Birth Defects and Developmental Disabilities (CDC)Authors: Jennifer Lynn Williams, C.J. Alverson, Kathryn B. Anderson, Margaret A. Watkins, Adolfo Correa

C2.3. Title: Spatial Analysis of Birth Defects in Atlanta **Program:** National Center on Birth Defects and Developmental Disabilities (CDC) **Authors:** Csaba Siffel, C.J. Alverson, Adolfo Correa

C2.4. Title: Case Fatality Among Infants With Congenital Malformations by Lethality **Program:** Colorado Responds To Children With Special Needs **Authors:** Kirk Bol, Russel Rickard, Russ Kirby

C2.5. Title: Neural Tube Defects Among Infants Born to US Military FamiliesProgram: Department of Defense Birth and Infant Health RegistryAuthors: Rosha Aran, William K. Honner, Brianna Alexander, Kathy M. Campbell, Robert J. Reed, TylerC. Smith, Margaret A. K. Ryan

C2.6. Title: The Influence of Prematurity and Intrauterine Growth on the Risk for Birth Defects **Program:** Florida Birth Defects Registry **Authors:** Kimberlea W. Hauser, Charles A. Williams, Robert M. Nelson, Jr., Jaime L. Frías

C2.7. Title: Livebirths with Neural Tube Defects: Combined Impact of Prenatal Diagnosis and Folic Acid UtilizationProgram: Greenwood Genetic CenterAuthors: Roger E. Stevenson, Laurie H. Seaver

C2.8. Title: Neural Tube Defects and Associated Anomalies **Program:** Greenwood Genetic Center **Authors:** Julianne S. Collins, Roger E. Stevenson, Laurie H. Seaver, Jane H. Dean

C2.9. Title: Precurrence Risk of Birth Defects in Hawaii **Program:** Hawaii Birth Defects Program **Authors:** Mathias B. Forrester, Ruth D. Merz

C2.10. Title: Rates for Specific Birth Defects Among Native Hawaiians Compared to Whites **Program:** Hawaii Birth Defects Program **Authors:** Mathias B. Forrester, Ruth D. Merz

C2.11. Title: Prevalence Rates of Selected Structural Anomalies in Kentucky, 1998 – 2001 **Program:** Kentucky Birth Surveillance Registry **Authors:** Joyce M. Robl, Sandy G. Fawbush, Tracey Jewell

C2.12. Title: An Evaluation of the Leading Causes of Death and Relative Risk of Death by Underlying Cause of Death Grouping Among Infants and Children with Reportable Conditions **Program:** Michigan Birth Defects Registry **Author:** Glenn Copeland

C2.13. Title: Results of Neural Tube Defects Case Ascertainment Process Combining Vital Records Datasets and Birth Defects Surveillance Data for Years 1996 to 2001, in Puerto Rico **Program:** Puerto Rico Folic Acid Campaign and Birth Defects Surveillance System **Authors:** Hector I. Garcia, Elia M. Correa, Diana Valencia

C2.14. Title: Multiple Gestation and Neural Tube Defects

Program: The South Carolina Neural Tube Defect Surveillance and Prevention Program **Authors:** Laurie H. Seaver, Roger E. Stevenson, Julianne S. Collins, Jane H. Dean

C2.15. Title: Patent Ductus Arteriosis and Premature Births 1996-2000 **Program:** West Virginia Birth Defects Surveillance System and Vital Statistics **Author:** Melissa A. Baker

Category 3: Prevention, Intervention, and Public Policy

C3.1. Title: Linking Infants with Birth Defects to Early Intervention Services via the Medical Home **Program:** Alabama Birth Defects Surveillance and Prevention Program **Authors:** Wladimir Wertelecki, Margaret Hilliard

C3.2. Title: Establishing a Statewide Folic Acid Education and Distribution Program for Low-Income Women

Program: Arizona Birth Defects Monitoring Program **Authors:** Allison K. Varga, Timothy J. Flood

C3.3. Title: Perceived Barriers to the Post-Gestation Continuance of Supplemental Folic Acid: Survey Results from a Teratogen Information Line
Program: California Teratogen Information Service Pregnancy Risk Information Line
University of California, San Diego
Authors: Beck B. Goldberg, Sonia Alvarado, Carmen Chavez, Brian H. Chen, Lyn M. Dick, Robert J. Felix, Kelly K. Kao, Kenneth Lyons Jones, Christina D. Chambers

C3.4. Title: Developing a Birth Defects Prevention Educational Material for a Population with Low to Average Literacy Skills: Lessons Learned from "Emma's Story"
Program: Birth Defects Division, Prevention Research and Health Communications Team, National Center on Birth Defects and Developmental Disabilities (CDC)
Author: Katie Kilker

C3.5. Title: Evaluation of the Folic Acid Module in the Behavioral Risk Factor Surveillance System (BRFSS): Are We Getting the Bang for our Buck? **Program:** Epidemic Intelligence Service; Epidemiology Program Office¹, National Center on Birth Defects and Developmental Disabilities² (CDC) **Authors:** Kathleen Green Raleigh^{1,2}, Christine Prue², Joe Mulinare²

C3.6. Title: Evaluation and Changes of Folic Acid Messages used in Puerto Rico **Program:** Folic Acid Campaign and Birth Defects Surveillance System, Puerto Rico Department of Health **Authors:** Elia M. Correa, Diana Valencia, Hector I. García

C3.7. Title: The Iowa Birth Defects Registry Parent Notification System: Six Months of Experience **Programs:** Iowa Department of Public Health and the Iowa Birth Defects Registry **Authors:** Tammy O'Hollearn, Tonya Diehn, Paul Romitti, Kim Keppler-Noreuil

C3.8. Title: Health Care Professionals Knowledge and Practices Regarding Folic Acid **Program:** March of Dimes Birth Defects Foundation **Authors:** Stephen M. Abelman, Karla Damus, Jennifer Williams, Cheryl Stone

C3.9. Title: Michigan Children with Birth Defects: The Role of Hospitals in Linking Families with Services **Program:** The Michigan Birth Defects Registry (MBDR): Prevention, Monitoring and Follow-up **Authors:** Jane Simmermon, Lorrie Simmons, Janice Bach, Glenn Copeland

C3.10. Title: Life Long Happiness: A Preconception Health Education Project Helping Women Make Healthy Choices **Program:** New Mexico Birth Defects Surveillance and Prevention Program **Authors:** Maggi Gallaher, Jean Higgins

C3.11. Title: Follow-up Survey on Parents of Children with Major Birth Defects in New York State **Program:** New York State Congenital Malformations Registry **Authors:** Monica Sharpe-Stimac, Ying Wang, Charlotte M. Druschel, Philip K. Cross

C3.12. Title: Association Between Maternity Care Coordination Services and Referral to the Child Service Coordination Program Among Infants with Craniofacial Anomalies **Program:** North Carolina Birth Defects Monitoring Program **Authors:** Cynthia Cassell, Robert Meyer, Fatma Simsek, Anita Farel

C3.13. Title: Spina Bifida Recurrence Prevention Efforts and Progress **Program:** Spina Bifida Association of America, Recurrence Prevention Campaign **Author:** Adriane K. Grifen

C3.14. Title: Birth Defects in the News: A Content Analysis of U.S. Daily Newspapers **Programs:** Texas Department of Health¹, Public Policy Research Institute² – TAMU **Authors:** Amy P. Case, Michael Voloudakis, Ann F. Phelps

Category 4: Program Methodology – Advisory Committees, Legislation, Planning

C4.1. Title: Comparison of Birth Defect Reporting Trends Between Passive and Active Case Ascertainment Methods at a Minneapolis Hospital
Program: Minnesota Department of Health Birth Defects Prevention and Information Program
Authors: Myron Falken, Daniel Symonik, Richard Lussky, Nancy Mendelsohn, Maureen Alms, Emily Hansen

C4.2. Title: Accomplishments in Surveillance Revitalization, 2000 – 2003 **Program:** Washington State Birth Defects Surveillance System **Authors:** Riley Peters, Jeanette Robbins, Civillia Winslow Hill

Category 1: Case Ascertainment – Innovative Approaches, Use of Physician Office Data, Prenatal Surveillance, Pediatric Cardiac Registries; Environmental Data

C1.1. Illinois Adverse Pregnancy Outcome Reporting System (APORS)

Hospital Staff Training and the Impact on Passive Reporting of Birth Defects and Other Adverse Pregnancy Outcomes

Carole Strainis, Jane E. Fornoff

Objective: The APORS relies on hospital reporting of birth defects and other adverse pregnancy outcomes as the primary source of cases. Since 2001, the APORS trainer has been conducting training at hospitals to improve case identification and report accuracy.

Methods: The APORS trainer visits facilities where (1) a reporting problem has been observed, (2) changes in staff responsible for reporting have occurred, (3) in-service requests have been made; and (4) to facilities with a neonatal intensive care unit. The trainer uses hospital-specific results from APORS quality assurance studies and hospitals' reporting history to design training. One-on-one meetings and group trainings of nurses and/or medical record department staff are held. Techniques used range from formal presentations to change-of-shift meetings. The training content varies according to each facility's strengths and weaknesses, but always includes a detailed review of the case definition. The trainer emphasizes that each case is referred for follow-up services as well as contributes to public health surveillance. Facility staffs are urged to work with medical records units to assure more complete case identification. Evaluation of the effect of this training is difficult because of concurrent quality improvement projects.

Results: The number of children reported by facilities has increased from 8.8% of births in 2000 to 9.6% of births in 2002. The number of very low birth-weight children unreported to APORS (determined by matching to vital records) has decreased by more than 25% between 1999 and 2002. More information is needed to determine the impact on birth defect reporting. Regular visits to facilities have made it easier for their staff to ask questions of APORS. In turn APORS staff are more aware of the difficulties hospital staff face, and can clarify areas that are often not understood.

Conclusions: Training hospital staff in reporting requirements can be effective in increasing case identification and quality of hospital reporting. It is a time-consuming process and has to be ongoing because of the rapid rate of staff changes at facilities.

C1.2. Massachusetts Center for Birth Defects Research and Prevention Massachusetts Birth Defects Monitoring Program (MBDMP)

Supplemental Approaches to Case Ascertainment in Massachusetts I: Ascertainment of Cardiovascular Malformations from Outpatient Cardiology Clinics

Angela Lin, Elizabeth Bingay, Cathleen Higgins, Sudha Karamuri, Marlene Anderka

Objective: Ascertaining cardiovascular malformations (CVMs) using inpatient and day surgery medical records may omit patients with mild CVMs who are followed solely on an outpatient basis, not needing admission for an invasive procedure or surgery. We tracked patients with ICD-9 cardiac codes identified from outpatient clinic lists for inclusion into surveillance, as well as possible eligibility in the National Birth Defects Prevention Study (NBDPS), an ongoing collaboration in which Massachusetts participates.

Methods: A cohort of infants who were < 1 year on Jan. 1, 2002 were followed from July 1, 2002 until Oct. 31, 2003 (16 months) to determine if they had been ascertained by the MBDMP. We identified them from outpatient clinic lists, and abstracted information from medical records.

Results: Of 545 infants seen in assorted outpatient specialty clinics at the largest pediatric referral center in Massachusetts, 147 had a CVM code, 53 (36%) of whom were already in the MBDMP database. Of the remaining 92 (63%) not in the current database, we identified 11 (12%) infants for surveillance (4 secundum type atrial septal defect, 3 membranous ventricular septal defect, 1 each pulmonic stenosis, aortic stenosis, unspecified VSD, transitional atrioventricular canal defect); these infants are also eligible for the NBDPS. Medical record review determined that 81 infants identified as having a "cardiac code" failed to meet our criteria for surveillance. The most common reasons were muscular VSD (24), patent foramen ovale (14) and clinically diagnosed patent ductus arteriosus without echocardiography (10).

Conclusions: Incorporating cardiology outpatient clinic lists can provide a source of additional case ascertainment for population-based state surveillance (11 of 92, 12%). Medical record review remains an essential component of case clarification, in part, because of the limitations of ICD-9 coding for CVMs and the idiosyncracies of individual hospital coding practices.

C1.3. Massachusetts Center for Birth Defects Research and Prevention Massachusetts Birth Defects Monitoring Program (MBDMP)

Supplemental Approaches to Case Ascertainment in Massachusetts II: Targeting Ascertainment Activities: Finding MA Birth Defect Cases in Rhode Island

Cathleen Higgins, Joseph Burgio, Linda Casey, Marlene Anderka

Objective: To determine improvements in case ascertainment when surveillance is expanded to include one major birthing hospital and one major tertiary care hospital near the Massachusetts border in an adjoining state.

Methods: In 2000, 1318 births occurred to MA residents at out of state hospitals. Of these births, 68.9% occurred in Rhode Island (RI) hospitals. In order to capture data on infants with birth defects residing in the southeastern region of Massachusetts that were born or treated at RI hospitals, we began receiving hospital discharge lists and abstracting medical records on infants with birth defects at two RI hospitals. Birth defects prevalence was examined with and without the RI hospital data to assess improvements in ascertainment.

Results: In 2000, with data acquired from the two RI hospitals, 41 cases were newly diagnosed, confirmed or received a different diagnosis in southeastern Massachusetts. Without the RI data, there were 213 cases with birth defects for a prevalence rate of 140.0 per 10,000 live births. After adding the RI hospital data there were 254 cases with birth defects, increasing the prevalence rate to 166.9 per 10,000 live births. This represents a 19% increase in both the number of birth defect cases as well as the prevalence rate. Twenty percent of all gastroschisis cases were diagnosed or confirmed in RI, representing 60% of gastroschisis cases for the southeastern region. Twenty-four percent of secundum atrial septal defects in the southeastern region were either diagnosed or confirmed in the Rhode Island hospitals.

Conclusions: Including border states into surveillance programs enhances complete and accurate case ascertainment.

C1.4. Massachusetts Center for Birth Defects Research and Prevention Massachusetts Birth Defects Monitoring Program (MBDMP)

Supplemental Approaches to Case Ascertainment in Massachusetts III: Faster Ascertainment by Faxing Queries to Physicians

Joseph Burgio, Angela Lin, Cathleen Higgins, Susan Winship, Linda Casey, Marlene Anderka

Objective: To develop a method to quickly and easily get specific diagnostic data from physicians.

Methods: Data extracted from hospital records is often incomplete, and thus, information from diagnosing physicians is essential in order to clarify the disposition of a case. Based on anecdotal experience from our staff, telephone calls to physician offices were a slow method of gathering information due to "telephone tag". Email is not HIPAA compliant, and the technology needed to secure it is being adopted slowly. We contacted physicians using a one-page fax. An official DPH letterhead cover sheet with explanatory HIPAA paragraph accompanied each fax query. At the bottom of the fax page, the program's clinical geneticist asked for clarification of a specific defect using check-off boxes to encourage a prompt reply. In addition to a "generic" fax, we also designed template queries for two common defects requiring follow-up, i.e. craniosynostosis and hypospadias.

Results: Preliminary analysis was based on 121 faxes sent from January 1, 2003 through August 31, 2003. We received 82 (68%) responses. The average response time was about 11 days, with 80% of responses occurring within two weeks. Of 68 cases who had already entered the surveillance system, 58 (85%) met criteria for inclusion in the surveillance database, 5 were rejected after being identified as a "probable" case, 5 remain pending. Fourteen "possible" cases were rejected with minimal or no abstraction before entering the surveillance system.

Conclusions: A single page fax query is a simple, effective, and adaptable method to rapidly obtain brief but crucial diagnostic information used for determining case disposition.

C1.5. Oklahoma Birth Defects Registry

Geographic Information System Analysis of the Association Between Environmental Quality and Neural Tube Defects in Oklahoma

Kay Pearson, Rosina Everitte*

Objective: To determine if there is a spatial-temporal association between environmental toxins from archived EPA voluntary sites, Superfund sites, and current industries reporting permitted emission releases (air, soil, and water) and neural tube defects (NTDs), spina bifida and anencephaly.

Methods: 1994 through 2000 provisional data for ICD-9 CM codes 74000-740290 and 741000-741990 were reviewed to identify 273 cases. A state map containing county coordinates, lake and river coordinates, and five digit zip code coordinates was used to display the spatial-temporal association between the emission sites and the NTD cases. Resident addresses and emission site locations were geo-coded at the street level, although some rural data had to be geo-coded at the zip code level. Potential clustering was initially assessed and where possible, zip code coordinates were geo-coded at the street level for these data representing possible clustering through GPS mapping in the field.

Results: The GIS visual map displays the state of Oklahoma by county and zip code ranges. When a county demonstrated higher than normal NTD incidence rates for either one-year or two-year groupings, that county was further explored as to the locality of the cases in question. A four-mile exposure radius around the reported NTD cases was established to identify emitting industries that may be correlated with the high NTD rates. If the cases in question differed by more than two years in occurrence, clustering(s) was assumed to be non-existent and the county was disregarded. A matrix was constructed containing emitting industries within the four-mile radius, what emissions were expelled (where possible), how the emissions were expelled, and how many cases were in the four-mile radius of the industry in question. Statistical analysis of the data will be performed to assess clustering.

Conclusions: Use of county and zip code ranges can identify clustering of NTDs around specific emission sites; however, it will not identify the precise location of each NTD case in relation to the site. To identify a clustering around the sites, the precise street address must be shown in bullet form. Where applicable, most addresses listed as rural routes were coded using a Geo-Explorer III to determine latitude and longitude, allowing them to be included in the street address mapping. Because of the state's rural nature, this has proven to be a time constraint limitation of GIS in Oklahoma. Due to the rare nature of NTDs, cases that could not be identified by a street address or latitude and longitude were included in the exposure proximity circle map with zip code coordinates and are interpreted with caution and documented accordingly. Approximately 10,000 emission sites throughout the state have been documented and a yet-to-be-determined number of these will be identified as having NTD clusters within the criteria stated above. Emissions from those sites are currently being compared to determine the chemical content, as well as vehicle, of the emission.

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C1.6. Texas Center for Birth Defects Research and Prevention

Medical Records vs. Interview Responses: A Comparative Analysis of Selected Variables for Linked Birth Defect Cases

Mark A. Canfield, Tunu Ramadhani, D. Kim Waller, Amy P. Case

Objectives: To compare and assess the prevalence, agreement, sensitivity and specificity of selected factors ascertained on mothers of infants with birth defects using two different sources of data: the Texas Birth Defects Registry (TX-BDR) and Texas component of the National Birth Defects Prevention Study (TX-NBDPS).

Methods: The TX-BDR, based on the medical records of mothers and infants, and the TX-NBDPS, based on phone interviews with mothers, were linked for 1,017 deliveries from October 1997 through 2000. We examined gestational diabetes, non-gestational diabetes, seizures/epilepsy, insulin use, pregnancy history, and Hispanic ethnicity.

Results: The prevalence of maternal non-gestational diabetes was similar in the TX-BDR (4.3%) and the TX-NBDPS (3.4%), with a high level of agreement between the two systems (kappa = 0.8). The prevalence of gestational diabetes was 7.9% and 9.2% in the two databases, respectively, with a kappa = 0.6. The prevalence of insulin use was 5.9% for TX-BDR case mothers, but slightly higher (7.2%) for the same mothers when interviewed (TX-NBDPS) (kappa = 0.8). Using the TX-BDR based on medical records as the standard, the sensitivity of the interview-based TX-NBDPS for non-gestational diabetes, gestational diabetes, and insulin use were 68.2%, 72.5%, and 93.3%, respectively. Using the TX-NBDPS as the standard, the sensitivity of the same factors was 85.7%, 61.7%, and 76.7%, respectively.

Conclusions: The availability of two distinct sources of data on the same cases provides an exceptional opportunity to compare and validate both databases. We found that certain variables were more completely and accurately ascertained from case mother interviews, while in other circumstances the information from the medical record information might be more accurate.

C1.7. Utah Birth Defect Network

Congenital Heart Defect Prevalence and Reporting in Utah, 1999-2002

Marcia Feldkamp^{1,2}, Luciana Young², Lynne MacLeod³, and John C. Carey¹ University of Utah Health Sciences Center, Division of Medical Genetics¹; Children's Memorial Hospital, Chicago, Illinois², and Utah Birth Defect Network, Utah Department of Health³

Objective: To evaluate prevalence and accuracy of reporting sources for congenital heart defect (CHD) cases identified to the Utah Birth Defect Network (UBDN) from January 1999 to December 2002. Reporting sources will be stratified by pre- and postnatally diagnosed cases to assess whether time of diagnoses alters reporting source frequency.

Methods: The UBDN began identifying all CHDs in 1999, except isolated ventricular septal defect (VSD). Using multiple sources, potential CHD cases reported to the UBDN were identified. Mothers not Utah residents at delivery were excluded. A pediatric cardiologist (LY) reviewed clinical information, echocardiogram reports, and operative reports of potential cases and classified the CHD into one of several pathogenetic categories. For this analysis, a hierarchy was created should an infant fit into more than one cardiac category.

Results: A total of 1,856 potential cardiac cases were identified during this time period. Of these potential cases, 1,091 (59%) met case criteria and 765 (41%) did not meet case criteria. Of those that did not meet case criteria, most were reported as either an atrial septal defect or pulmonary stenosis. Prevalence for all CHD was 5.7 per 1,000 births. 22.3% were reported by only one of the many sources; 27.4%, two; and 18.9%, three. For those cases with only one source, the majority was reported by the pediatric cardiology clinic (69%). The median number of reporting sources was two, with a range of 1-10.

Total and birth prevalence as well as source value will vary by specific cardiac lesion. Multiple reporting sources are required to capture all CHDs. Overall, 74% of cases were identified from the pediatric cardiology clinic, followed by birth certificate (52%), newborn intensive care nursery (48%), and pediatric hospital discharge data (45%).

Conclusions: Accuracy of CHD reporting will vary by defect and the reporting source. Informative reporting sources will vary based on the pregnancy outcome. Live born cases were frequently identified by the pediatric cardiology clinic; prenatal sources and fetal death certificates identified stillborn cases and; pregnancy terminations were identified more frequently by pathology and prenatal sources.

Category 2: Birth Defects Rates and Trends – Graphical Presentation of Data, Statistical, Cluster Evaluations

C2.1. National Center on Birth Defects and Developmental Disabilities (CDC)

A Method of Weighted Proportion of Reproductive-Aged Women Taking Folic Acid Supplements to Predict Neural Tube Defects Rate Decline

Quanhe Yang, Michael Atkinson, J. David Erickson

Background and Objective: Neural tube defects (NTDs) rates can be lowered by increased consumption of folic acid by women before and during early pregnancy. The crude proportion of reproductive-aged women taking folic acid supplements has been used to predict NTDs rate decline in the general population. This study examined the potential error in using the crude proportion to predict NTDs risk reduction and offers an alternative method.

Method: The crude proportion measures the number of women taking folic acid. It ignores the substantial variability by maternal age in the probability of giving birth. Age-specific fertility rates (ASFRs) reflect the probability that a woman in a specific age group will give birth in a given year. In this study, we showed how to calculate a proportion weighted by ASFRs to predict NTDs rate decline and to assess the effectiveness of folic acid consumption in preventing NTDs.

Results: Our results showed that a crude proportion of 50% of women (aged 15 through 49 years) taking folic acid was associated with a range of 24% to 77% in weighted proportions. Assuming a 40% risk reduction from taking 400 microgram (μ g) folic acid daily, the expected NTDs rate decline could vary from 9.6% to 30.6%, depending on the age distribution of women taking folic acid.

Conclusions: The ASFR-weighted proportion estimates the proportion of babies born to women taking folic acid as opposed to the crude proportion of women taking folic acid. We recommend using the ASFR-weighted proportion to predict NTDs rate decline and to measure the success of folic acid education campaigns. We showed that if women in high fertility age groups increased their folic acid consumption, the decline in NTDs rate was greater than if women in low fertility age groups did so. Our findings suggest that the most cost-effective approach to NTDs prevention is to focus on women with a higher probability of giving birth. For example, by focusing on less than 50% of childbearing-aged women (20 through 34 years of age), as much as 76% of the maximum NTDs rate reduction can be achieved.

C2.2. National Center on Birth Defects and Developmental Disabilities (CDC)

Prevalence of Maternal Diabetes in Metro Atlanta, 1968-2000

Jennifer Lynn Williams, C.J. Alverson, Kathryn B. Anderson, Margaret A. Watkins, Adolfo Correa

Objective: Maternal diabetes is associated with adverse pregnancy outcomes, including a 2-3 fold increased risk for major birth defects. Diabetes prevalence among child-bearing aged women is increasing, but population-based data on diabetes among pregnant women is limited. The objective of this analysis was to determine if the prevalence of diabetes during pregnancy has changed over time among childbearing-aged women in Metro Atlanta.

Methods: We studied diabetes prevalence among women who delivered infants without birth defects in three Atlanta population-based case-control birth defect studies conducted in 1968-1980(n=3023), in 1993-1996(n=301), and in 1997-2000(n=296).

Results: The prevalence of diabetes in pregnancy has risen overall: 1.1% (95% CI 0.8-1.5% [1968-1980]), 6.3% (95%CI 4.02-9.70% [1993-1996]), 6.1% (95% CI 3.8-9.5% [1997-2000]). The prevalence increased from 1.9% to 4.5% in black women (BW) and 0.9% to 7.1% in non-black women (NBW). The proportion of diabetic women diagnosed during pregnancy rose from 42% to 87%, representing an increase from 77% to 85% (BW) and 20% to 88% (NBW). The proportion of diabetic mothers classified as overweight/obese increased overall from 15.2% to 50%; representing an increase from 15% to 80% (BW) and 15% to 38% (NBW). The mean age of all mothers increased (25.7 to 28.7 years). NBW were consistently older than BW, and diabetics were consistently older than non-diabetics. Additional factors associated with diabetes in pregnancy across all studies included: being overweight/obese and multiparous.

Conclusions: The prevalence of diabetes- affected pregnancies in the Atlanta metro area has increased. This increase may be in part related to increasing maternal age and obesity prevalence and in part to evolving prenatal care practices. These findings extend the data on diabetes affected pregnancies and have important implications for preconceptual/prenatal care in the prevention of diabetic embryopathy.

C2.3. National Center on Birth Defects and Developmental Disabilities (CDC)

Spatial Analysis of Birth Defects in Atlanta

Csaba Siffel, C. J. Alverson, Adolfo Correa

Objective: To evaluate the feasibility of using birth defects surveillance data and census data for identifying spatial aggregation of high rates of birth defects in metropolitan Atlanta.

Methods: We examined data from the Metropolitan Atlanta Congenital Defects Program (MACDP), a population-based surveillance program of birth defects among infants born to residents of five counties in metropolitan Atlanta. Infants with birth defects (cases) born between 1968 and 2000 were geocoded by assigning longitude/latitude (x,y) coordinates to the mother's residence at the time of delivery. For this analysis, we included cases born in 1990 (n=1,266) among 38,779 recorded live births. The geocoded database was linked with a digitalized map of the five-county metropolitan Atlanta area. Using a geographic information systems (GIS) software package (ArcView), we aggregated cases of all birth defects by census tract for 368 census tracts and linked the geocoded dataset with the 1990 census by census tract (total infants = 29,444). Census-specific prevalence rates were computed based on the infant age group as a proxy of live births for census tracts. We used SaTScan, a statistical software, to scan for possible clusters birth defects (increased relative risks, RR) based on the Poisson distribution.

Results: The overall prevalence of birth defects in the study area was 4.33 per 100 infants. Maps of all cases of birth defects by census tract showed aggregation of high rates in small areas, with high rates identified for several census tracts. The scan statistics identified three possible clusters: cluster 1, relative risk (RR) = 3.7 (p=0.030), cluster 2, RR =2.2 (p=0.097); cluster 3, RR=5.3 (p=0.197).

Conclusions: A GIS database of birth defects can be useful in evaluations of spatial variation of birth defects in a defined population. Use of census data to derive estimates of census tract specific denominators allows for exploration of possible clusters but findings need to be interpreted with caution as such estimates may underestimate the true denominator. Further work is warranted to identify more robust denominators.

C2.4. Colorado Responds To Children With Special Needs

Case Fatality Among Infants With Congenital Malformations by Lethality

Kirk Bol, Russel Rickard, Russ Kirby

Objective: Infant mortality rates continue to show that congenital anomalies are the leading cause of infant death in the United States. However, studies of factors contributing to increased mortality across different types of congenital anomalies have been limited. The objective of this study was to assess whether the likelihood of infant mortality varied by maternal race and ethnic group while considering the severity of the birth defect.

Methods: A retrospective cohort analysis was conducted using data from Colorado's statewide, populationbased birth defects surveillance system (CRCSN). The cohort included infants born between 1995 and 2000 to Colorado resident mothers, and who were diagnosed with a major congenital malformation, which was categorized into degree of lethality. Multiple logistic regression was performed for each level of lethality, and included the following potential explanatory variables: maternal race/ethnicity, clinical gestation, birth weight, maternal education level, maternal age, and sex of child.

Results: Within the low/very low lethality cohort, maternal race/ethnicity of Black/non-Hispanic was associated with increased risk of infant mortality, OR 2.81 (1.41-5.19), as were low and very low birth weight, OR 2.21 (1.12-4.04) and 19.31 (11.84-31.01), respectively. Maternal race/ethnicity was not a significant risk factor in either high or very high lethality groups; however, the interaction between birth weight and gestational age significantly increased the risk of mortality.

Conclusions: Through the use of statewide, population-based birth defects surveillance data, a disparity in infant mortality has been identified in a specific subset of the population that could be investigated further and targeted for prevention activities.

C2.5. Department of Defense Birth and Infant Health Registry

Neural Tube Defects Among Infants Born to US Military Families

Rosha Aran, William K. Honner, Brianna Alexander, Kathy M. Campbell, Robert J. Reed, Tyler C. Smith, Margaret A. K. Ryan

Objective: To describe the prevalence of, and factors associated with, neural tube defects (NTDs) among infants born to military families between 1998 and 2000, using surveillance data in the Department of Defense (DoD) Birth and Infant Health Registry.

Methods: Within the military healthcare system, more than 249,000 infants were born to active duty military parents between January 1998 and December 2000. Sixteen percent of infants were born to active duty women and 75% were born to civilian wives of active duty men. NTDs were defined by ICD-9-CM coding in infants' healthcare records. The prevalence of specific NTDs in relation to defined demographics, including infant gender, maternal age, race, multiple births, location of birth, branch of military service, and parents' military occupation, were calculated.

Results: The overall prevalence of NTDs among infants born to military families was consistent with prevalence data reported from US civilian surveillance systems. Factors associated with a higher prevalence of NTDs included advanced maternal age and multiple births. Some differences in prevalence were noted by geographic location of birth. Military service branch and parents' military occupations were not associated with differences in the appearance of NTDs among infants.

Conclusions: The overall prevalence of NTDs among infants born to military families was consistent with US rates of these birth defects over the same time period. Small geographic differences observed may be useful to focusing resources to promote folic acid awareness in some regions. Although no military-specific risk factors for NTDs were identified, research will continue in this area to address concerns of service members, especially those with recent deployment experiences.

C2.6. Florida Birth Defects Registry

The Influence of Prematurity and Intrauterine Growth on the Risk for Birth Defects

Kimberlea W. Hauser, Charles A. Williams, Robert M. Nelson, Jr., Jaime L. Frías

Objective: To investigate the association between prematurity and intrauterine growth and the prevalence of birth defects in a live birth cohort.

Methods: Using data from the Florida Birth Defects Registry, we compared the prevalence of birth defects among live births based on prematurity and fetal intrauterine growth (small for gestational age [SGA], appropriate for gestational age [AGA], and large for gestational age [LGA]). Infants with birth defects were defined as those with at least one ICD-9 CM code in the reporting categories used by the Centers for Disease Control and Prevention (CDC). The analysis group consisted of singleton live births born between January 1, 1996 and December 31, 1999, whose gestational age at birth was between 20 and 44 weeks. These infants were categorized by birth weight as SGA (<10th percentile), AGA (10th to 90th percentile), and LGA (>90th percentile) using published standards based on race (White/Black) and ethnicity (Hispanic) (Alexander, Kogan, and Himes., 1999). Infant gestational age was determined from the birth certificate. If that value was missing, gestational age: 20-23 weeks, 24-27 weeks, 28-32 weeks, 33-36 weeks, 37-41 weeks, and 42-44 weeks. Infants with missing gestational ages, birth weights, and racial origins not classified as White or Black, or designated as having a birth defect not part of the CDC categories were dropped from the final analysis dataset (n=53 769). The final analysis dataset contained 700 947 infants.

Results: Of the 700 947 infants, 8% (n=56 468) were premature (gestational ages between 20 and 36 weeks) and 3% (n=20 524) had a reported birth defect. In this cohort, 7.9% were classified as SGA, 83.4% as AGA, and 8.7% as LGA. The mean birth weight for infants with birth defects was 2046g compared to 2378g for those without birth defects (p<.0000). Infants born prematurely were 2.82 (95% CI 2.72, 2.93) times more likely to be born with a birth defect than term infants. Almost 14% of infants with birth defects were classified as SGA compared to 8% of those without birth defects. In addition, SGA infants with birth defects were more likely to be premature (28%) than SGA infants without birth defects (12%). The relative risk for birth defects for premature SGA infants was 2.99 (95% CI: 2.74, 3.26), for premature AGA infants 2.78 (95% CI: 2.67, 2.90), and for premature LGA infants 2.70 (95% CI 2.22, 3.29).

Conclusions: We found that premature infants born in Florida had a 2.82 higher risk of birth defects than full term infants. Rasmussen et al. (2001) reported similar results using data from the Metropolitan Atlanta Congenital Defects Program. In addition, our data indicate that the relative risk for birth defects is higher for premature infants than term infants in all intrauterine growth categories.

C2.7. Greenwood Genetic Center

Livebirths with Neural Tube Defects: Combined Impact of Prenatal Diagnosis and Folic Acid Utilization

Roger E. Stevenson, Laurie H. Seaver

Two major strategies for the prevention of neural tube defects have emerged during the past 30 years. The first combines pregnancy screening and prenatal diagnosis to identify affected pregnancies. Utilization of maternal serum testing for alpha fetoprotein and ultrasound examination of the fetus, the two principal means of identifying affected pregnancies, came into widespread use in the 1970's. The second prevention strategy focuses on increasing the intake of folic acid by either periconceptional supplementation or food fortification. This strategy has been promoted since the early 1990's.

The combined effect of these two prevention strategies has resulted in a marked reduction in the number of livebirths with neural tube defects in South Carolina and elsewhere. During the 10 year period 1992 - 2002 the overall rates of NTDs in SC decreased from 1.86 to 0.89 NTDs per 1000 livebirths and fetal deaths, this decreased rate being attributed to greater folic acid utilization and to other unknown factor(s). Among 564 NTD-affected pregnancies in this same time period 267 (47%) were prenatally diagnosed and the pregnancies interrupted. An additional 69 pregnancies (12%) resulted in spontaneous abortion or fetal death. Livebirths with NTDs were thus 228/497,123 livebirths and fetal deaths.

Based on the 1992 prevalence rate, 968 NTD pregnancies would be expected in SC over the 10 year period. Allowing for 118 spontaneous abortions or fetal deaths, 850 potential livebirths would be expected over the 10 years, whereas only 228 livebirths occurred, a 73 percent reduction. On the basis of the occurrence figures in SC, the larger share of this reduction (355 cases, 57%) may be plausibly attributed to greater access to folic acid and unknown factors which contribute to lowering the risk of NTDs; the lesser share (267 cases, 43%) due to prenatal diagnosis and pregnancy interruption.

C2.8. Greenwood Genetic Center

Neural Tube Defects and Associated Anomalies

Julianne S. Collins, Roger E. Stevenson, Laurie H. Seaver, Jane H. Dean

Investigation of NTDs with associated anomalies can be instructive in understanding embryonic development, identifying the causes of birth defects determining occurrence risks, and guiding expectations for the efficiency of prevention strategies. In a 10 year period (1992 – 2002) 564 NTD-affected pregnancies were identified in South Carolina. Among these, 97 (17%) were associated with other anomalies. Half (51, 52%) of these malformation complexes constituted recognizable syndromes of genetic or environmental cause. In the others (47 cases, 48%) the NTDs and associated defects were not believed to represent a recognizable syndrome. Most of the associated defects in this latter group plausibly represent secondary anomalies. Specifically, diaphragmatic hernia and abdominal wall defects appear secondary to truncal shortening or cervical retroflection, which limits the available abdominal and thoracic space. Facial clefting and cardiac defects appear secondary to disturbed cephalic neural crest. Only 13 NTDs with associated anomalies did not fall into one of these two categories (recognizable syndrome association and secondary malformation). Although periconceptional folic acid use may not protect against NTDs as part of genetic or environmental syndromes, this preventive strategy should reduce the prevalence of those defects which occur secondary to the NTDs.

C2.9. Hawaii Birth Defects Program

Precurrence Risk of Birth Defects in Hawaii

Mathias B. Forrester, Ruth D. Merz

Objective: To calculate the precurrence risk (risk among older siblings) for a variety of birth defects categories.

Methods: Using data from a population-based birth defects registry in Hawaii for deliveries during 1986-2000, the precurrence risk for any major birth defect, birth defects of the same organ system, and same specific birth defect were calculated for 9 major organ systems and 54 specific birth defects.

Results: The precurrence risk of any major birth defect (3.5%) was substantially less that the risk of any major birth defect among the entire population (4.7%). The precurrence risk of a birth defect of the same organ system was significantly higher than the reference rate for 6 (67%) of the major organ systems. The precurrence risk of the same birth defect was substantially elevated for 15 (28%) of the specific birth defects.

Conclusions: Precurrence risk of any major birth defect was not elevated but tended to be lower than expected. However, for a number of birth defects categories precurrence risk of birth defects of the same organ system or the same specific birth defect was substantially elevated.

C2.10. Hawaii Birth Defects Program

Rates for Specific Birth Defects among Native Hawaiians Compared to Whites

Mathias B. Forrester, Ruth D. Merz

Objective: To calculate rates of specific birth defects among native Hawaiians and compare them to rates among whites.

Methods: Data were obtained from an active birth defects surveillance system in Hawaii. The rates for 54 specific birth defects were calculated for deliveries to native Hawaiian and white mothers and compared after adjusting for maternal age distribution.

Results: Among 1986-2000 deliveries, the total major birth defect rate for whites was 4.70% (3,404 cases among 72,416 live births) and for native Hawaiians was 4.75% (3,004 cases among 63,291 live births) (adjusted relative risk of 0.87, 95% confidence interval 0.84-0.90). After adjusting for maternal age, the rates were lower among native Hawaiians for 40 (74.1%) of 54 selected birth defects, although this difference was significant for only ventricular septal defect (adjusted RR 0.83, 95% CI 0.74-0.94) and trisomy 21(adjusted RR 0.77, 95% CI 0.59-0.98).

Conclusions: After adjusting for maternal age, birth defect rates tended to be lower among native Hawaiians than among whites. Differences observed in rates for specific birth defects between native Hawaiians and whites might be due to chance or genetic or environmental differences between the two racial/ethnic groups.

C2.11. Kentucky Birth Surveillance Registry

Prevalence Rates of Selected Structural Anomalies in Kentucky, 1998 – 2001

Joyce M. Robl, Sandy G. Fawbush, Tracey Jewell

Objective: To determine the prevalence rates and geographical distribution of neural tube defects, oro-facial clefts, abdominal wall defects and chromosome anomalies in residents of the Commonwealth of Kentucky from 1998 to 2001.

Methods: Congenital anomalies are reported to the Kentucky Birth Surveillance Registry (KBSR) through vital statistics and hospital discharge data. Additional reporting sources include the two tertiary care neonatal intensive care units, genetics service providers throughout the state, and medical laboratories. Medical records abstraction has been completed on all cases identified with these conditions to verify the diagnosis and to obtain additional information about prenatal diagnosis, referral patterns and risk factors.

Results: The rates of these conditions for this four-year period of time are graphically presented along with geographical maps of the occurrence of these birth defects in Kentucky.

Conclusions: This is the first reliable data on birth defects in the Commonwealth of Kentucky. It will be utilized to establish baseline prevalence figures for these birth defects, to ensure that services such as early intervention and genetics outreach clinics are available in areas of Kentucky with the highest need, and for further epidemiological investigation by researchers.

C2.12. Michigan Birth Defects Registry

An Evaluation of the Leading Causes of Death and Relative Risk of Death by Underlying Cause of Death Grouping Among Infants and Children with Reportable Conditions

Glenn Copeland

Objective: To examine cause of death information for deaths to infants and children, comparing those with a reportable birth defect to others to determine if differences exist in mortality risk beyond the risk of death due to birth defects alone.

Methods: A cohort of deaths to children born between 1992 and 2000 in Michigan to Michigan resident mothers was developed that includes 12,523 such deaths occurring between 1992 and 2002. All deaths in the database were coded to ICD 9. Causes of death were grouped into the standard 282 cause code groupings used for ranking. The database was linked to the live birth and Michigan Birth Defects Registry (MBDR) files. The study file included 4,162 cases of death to children in the registry and 8,320 comparison cases.

Results: Significantly higher relative risk of death was observed for all cause of death categories with sufficient deaths to calculate rates. Significant differences were observed in relative rank and proportionate significance of disease categories between the children in the MBDR and other children. The MBDR cases comprised 32 percent of all infant deaths. Deaths due to intestinal problems, anemias, diseases of the heart (other than congenital anomalies), certain infections and cerebrovascular disease were all proportionately higher among MBDR infants. Findings were similar for children dying after the first year, except for neoplasms. Benign neoplasms were relatively lower while malignant neoplasms were higher among MBDR infant deaths, a finding that was reversed for MBDR deaths over 1 year. Proportions of accidental, homicide and bronchitis deaths were relatively higher among non-MBDR cases.

Conclusions: The elevated mortality experienced by children with birth defects is manifested in higher morality rates across all cause categories suggesting that management of these at risk children must be comprehensive. The causes of death that present the greatest risks for death to MBDR children are different from other children in distinct ways which may relate to the underlying health status of the children.

C.2.13. Puerto Rico Folic Acid Campaign and Birth Defects Surveillance System

Results of Neural Tube defects Case Ascertainment Process Combining Vital Records datasets and Birth Defects Surveillance data for years 1996 to 2001, in Puerto Rico.

Hector I. Garcia, Elia M. Correa, Diana Valencia

Objective: To evaluate the Birth Defects Surveillance System (BDSS) case ascertainment process for potential neural tube defects (NTD) cases in the vital records including live births, fetal deaths and death certificates to maximize data validity and reliability.

Methods: Data from the Vital Records Office were decoded from an ASCII file using a layout and syntax designed in SPSS and then linked to the BDSS data. 198 cases with NTD's were considered from the vital records datasets and 405 from BDSS. A match with the BDSS data was done by using delivery date, child's and parents names, and, social security number.

Results: For the years 1996 to 2001, 93%(405/435) of all NTD cases were found through the existing hospital based surveillance. An additional 7%(30/435) of cases were found from vital records. Of 198 potential cases found in the vital records datasets with possible NTD diagnosis, 53%(110) were matched with BDSS data. From among the remaining 88 cases, 15%(30) were confirmed as NTD cases in hospital records, 5%(10) did not meet the NTD case definition and 27%(49) were pending hospital record review by case abstractors. Surveillance case detection for NTD cases had a high sensitivity of 93%(405/435) and predictive positive value of 98%(405/415)

Conclusions: Very high ascertainment (93%) of NTD cases was achieved through surveillance. Although it proved to be an effective source for NTD abstraction, vital records contributed with abstracting an additional 7% of NTD cases. Although most of the NTD cases have been ascertained through epidemiological surveillance, we shall also rely on vital records as an additional source of NTD ascertainment in Puerto Rico.

C.2.14. The South Carolina Neural Tube Defect Surveillance and Prevention Program

Multiple Gestation and Neural Tube Defects

Laurie H. Seaver, Roger E. Stevenson, Julianne S. Collins, Jane H. Dean

Objective: To investigate the contribution of multiple gestation to neural tube defects (NTDs) in South Carolina.

Methods: Active and passive surveillance methods and multiple source ascertainment are used to determine the prevalence of NTDs in South Carolina among live births and fetal deaths. Information collected includes the presence of multiple gestation. Specific information collected on the multiple gestation pregnancies included maternal age, parity, number of fetuses, sex of fetuses, type of NTD, associated anomalies, karyotype if performed, zygosity based on ultrasonography of placental and fetal membranes or pathologic examination of the placenta and pregnancy outcome. Total number of live births, fetal deaths, and multiple gestations is obtained from birth certificates. The rates of NTDs among multiple gestations and singleton pregnancies and the rate of multiple gestation among NTDs were calculated for the study period. The male/female (M/F) sex ratio was calculated for NTD affected singleton and multiple gestation pregnancies.

Results: 20 multiple gestation pregnancies resulting in 21 NTD affected fetuses were among the 564 NTD ascertained from 1992-2002. The NTD rate among multiple gestation pregnancies is 1.4/1000 compared to the singleton NTD rate of 1.1/1000. There were 18 twin (2 conjoined), 1 triplet and 1 quadruplet pregnancies. There was 1 (5%) concordant pregnancy. There were 12 like-sexed, 4 unlike-sexed, and 4 unknown sex pregnancies. The M/F ratio was 0.8 among the multiple gestation pregnancies (3 or 15% unknown) and 0.8 among the singleton pregnancies (11% unknown). Among the multiple gestation pregnancies, there were 9 cases of an encephaly (M/F 0.5), 11 spina bifida (M/F 1.2) and 1 encephalocele (1 monozygous F). There were 7 twin gestations (all monoamniotic) and 1 diamniotic/monochorionic/dizygotic/dizygotic quadruplet gestation in which the affected was one of the monozygous pair, 4 dizygotic gestations and 8 of unknown zygosity (5 like-sexed, 3 unknown). Three affected infants/fetuses had associated anomalies, both sets of conjoined twins (diaphragmatic hernia, cleft lip) and twins discordant for OEIS sequence.

Conclusion: Our data support previous observations that multiple gestation, especially monozygosity, is a common association/contribution to NTDs. Late division, indicated by monoamniotic gestation is much more common that expected (typically 1-2% of monozygous gestations) and thus may indicate a potential explanation or mechanism for this association.

C2.15. West Virginia Birth Defects Surveillance System and Vital Statistics

Patent Ductus Arteriosis and Premature Births 1996-2000

Melissa A. Baker

Objective: Patent ductus arteriosus (PDA) occurs when a blood vessel that is normal while a baby in the womb fails to close after the baby is born. The cause of the problem is not known and it affects one in 2000 babies that are born each year. It is much more common in premature infants. This study examines patent ductus arteriosis and premature birth data from West Virginia.

Methods: Using data from the WV Birth Defects Surveillance System and Vital Statistics we looked at the prevalence of patent ductus arteriosis and premature births from 1996 through 2000. Results are stratified by race, Caucasian and African American.

Results: Data from 1996 - 2000 indicate patent ductus arteriosis accounted for 91 Caucasian cases and 2 African American cases in 1996, 132 cases for Caucasian and 2 for African American in 1997, 84 for Caucasian and 2 for African American in 1998, 68 for Caucasian and 4 for African American in 1999 and 84 for Caucasian and 3 for African American in 2000. This reflects an overall rate for 1996-2000 of 46.7 per10,000 for Caucasian and 37.3 per 10,000 for African American. Premature births were 11.1% for Caucasian and 17.3% for African American in 1996, 12.1% for Caucasian and 18.7% for African American in 1997, 12.2% for Caucasian and 15.6% for African American in 1998, 12.5% for Caucasian and 20.9% for African American in 1999 and 12.3% for Caucasian and 20.0% for African American in 2000.

Conclusions: The occurrence of patent ductus arteriosis and the prevalence of premature birth has not decreased in West Virginia in recent years. Premature birth can be reduced with prenatal counseling, education and care. Despite the proportion of pregnancies resulting in prematurity, expenditures for care of premature infants total an exorbitant amount compared to the cost incurred for all newborns. These data can be used to enhance understanding regarding premature infants and possible implications. These findings can be used to enhance existing and develop programs regarding prematurity. Reduction in premature births would result in an overall reduction in infant illness, disability and death.

Category 3: Prevention, Intervention, and Public Policy- Systematic Evaluation of Prevention Activities, Referral/Follow-up Services and Resources, Analysis of Public Policy, Analysis of Public Awareness, Use of Surveillance Data to Measure Outcomes

C3.1. Alabama Birth Defects Surveillance and Prevention Program

Linking Infants with Birth Defects to Early Intervention Services via the Medical Home

Margaret Hilliard, Wladimir Wertelecki

Objective: To develop a system to link infants with birth defects ascertained through surveillance to early intervention services via medical homes and to develop an evaluation tool to measure the effectiveness of such.

Methods: Following meetings with state agencies providing early intervention services to children with special health care needs we designed a letter to be mailed to medical homes of infants who might benefit from such services (we have no authority to contact families directly). Enclosed with the letter are brochures from Alabama's Early Intervention System, Children's Rehabilitation Services and the Genetics-Birth Defects Center as well as context specific information for both the medical provider and the family. To evaluate the effectiveness of the system and to measure satisfaction, a postcard is mailed to the medical home approximately one month after the letter. Recipients are asked to reply indicating whether or not the information is useful to them in their practice, if they have given or intend to give the information to the family, and if additional information is needed. If no postcard is received, a telephone call by the area birth defect surveillance nurse is made to obtain the evaluation data.

Results: In five months 25 letters were sent to medical homes of families residing in 13 counties with 733 pages of information. Of 20 follow-up postcards mailed, 100% indicated that the information given is useful in terms of medical practice, 83% indicated that they gave or intended to give the information to the family, and one requested information in Spanish. Two telephone calls have been made, one of which resulted in an invitation to visit the medical home.

Conclusions: Preliminary conclusions are that the approach described is an effective way to impact the medical home to improve access to care. We plan to monitor referral patterns to further assess the impact of this strategy.

C3.2. Arizona Birth Defects Monitoring Program

Establishing a Statewide Folic Acid Education and Distribution Program for Low-Income Women

Allison K. Varga, Timothy J. Flood

Objective: To increase the number of low-income women of childbearing age in Arizona that know about folic acid and its role in neural tube defect prevention, and to increase the number of these women that have access to multivitamins containing folic acid.

Methods: In 2001 the Arizona Department of Health Services (ADHS) obtained authorization to use \$800,000 of the state's Tobacco Litigation Master Settlement money to establish a folic acid distribution and education program through county health departments. The program is administered by the ADHS Office of Nutrition Services, which purchases and distributes supplements, trains health care providers, and provides fiscal oversight. Folic acid education and multivitamin distribution has been integrated into numerous county health department programs, including WIC, family planning and STD clinics. Each client receives a risk-assessment, one-on-one folic acid education and a free year-supply of multivitamins. Referrals are provided for women at high-risk for having a baby with a neural tube defect. County health department programs report on the number of their clients that correctly answer the majority of questions on a folic acid pretest and how many receive counseling and multivitamins each month. Client-specific reporting forms gather information about multivitamin use during each visit. However, this data is not currently reported to the State Health Department. County health department representatives meet quarterly at ADHS (the "Folic Acid Forum") to resolve concerns and share success stories.

Results: Since the program began in April 2002, it has provided one-on-one folic acid education and a yearsupply of multivitamins containing folic acid to over 24,000 low-income women, 43% of which were previously unaware of the benefits of periconceptual folic acid intake. Significantly more women were able to answer folic acid awareness questions correctly during a follow-up visit than were able to answer the questions correctly at the initial visit.

Conclusions and Implications: A large number of low-income women have been taught about the importance of adequate periconceptual folic acid intake for neural tube defect prevention and have received a year-supply of multivitamins. Even if funds are not available in the future to provide free multivitamins, county public health workers have integrated folic acid education into their routine client interactions and will continue to teach women about folic acid and its importance in neural tube defect prevention. The Folic Acid Forum will also continue to provide a setting where state and county health departments can collaborate for future folic acid education and birth defect prevention activities. It is hoped that these activities will help increase the number of women of childbearing age consuming adequate amounts of folic acid periconceptually and that the rates of infants born with neural tube defects in Arizona will significantly decline.

C3.3. California Teratogen Information Service Pregnancy Risk Information Line University of California, San Diego

Perceived Barriers to the Post-Gestation Continuance of Supplemental Folic Acid: Survey Results from a Teratogen Information Line

Beck B. Goldberg, Sonia Alvarado, Carmen Chavez, Brian H. Chen, Lyn M. Dick, Robert J. Felix, Kelly K. Kao, Kenneth Lyons Jones, Christina D. Chambers

Objectives: To explore the attitudes of pregnant women who call the California Teratogen Information Service (CTIS) toward continued use of folic acid supplements after delivery in order to improve protection in a potential future pregnancy, and to evaluate the feasibility of an intervention designed to encourage this behavior among callers to Teratogen Information Services nationwide.

Methods: A cross-sectional survey was conducted beginning August 12, 2003. Preliminary data from the two-month period ending December 16, 2003, are presented here. CTIS counselors asked all pregnant callers to complete a telephone interview regarding folic acid supplementation. Callers who were unwilling to complete the survey at the time of the call were offered an alternative time or a mailed survey. Frequency of responses were tabulated and summarized.

Results: Of the 645 pregnant callers who contacted CTIS during the study period, 278 (43%) women completed a survey. The ethnic distribution of responders was as follows: White non-Hispanic 55.6%, Hispanic 20.6%, Asian Pacific Islander 12.6%, Black non-Hispanic 2.5%, and Other 4.0%. Among these women, more than half (53.5%) were not taking folic acid supplements until after recognition of pregnancy or at all, and 57.2% reported that the current pregnancy was unplanned. Using multivariate logistic regression, lower maternal age, less than a high school education, and an unplanned pregnancy were strong and significant predictors of failure to initiate folic acid supplementation until after the sixth week of pregnancy in anticipation of a possible future pregnancy, if their physician suggested it. Of the reasons cited as barriers to continued folic acid use, 13.7% said that the price of vitamins would play a role, 19.1% said that it was too much trouble to take a pill every day, 27.3% said that vitamins caused digestive/stomach problems, 25.2% said they believed they were getting enough folate from their diet, and 32.4% did not plan to get pregnant again.

Conclusions and Implications: Given the high proportion of unplanned pregnancies, and the low prevalence of preconception folic acid supplementation in the CTIS respondents, a behavioral intervention trial conducted among currently pregnant women who call a Teratogen Information Service in the U.S. is both feasible and warranted.

C3.4. Birth Defects Division, Prevention Research and Health Communications Team National Center on Birth Defects and Developmental Disabilities (CDC)

Developing a Birth Defects Prevention Educational Material for a Population with Low to Average Literacy Skills: Lessons Learned from "Emma's Story"

Katie Kilker

Objective: To develop a birth defects prevention educational material that is appropriate and effective for people with low to average literacy skills.

Methods: Using knowledge gained from communications research, professional experience with the general public, and training opportunities, a "low-literacy" framework for the folic acid message was developed. Our message was designed to encourage women with lower literacy skills who are contemplating pregnancy to take folic acid daily to prevent neural tube defects. The health message was tested a number of times with community members from our target audience at a variety of locations in the metro Atlanta area. Audience feedback was incorporated as the material was revised.

Results: The constant reshaping of the folic acid booklet resulted in a colorful, photo-filled, easy to follow, and captivating educational material written at a 6^{th} grade reading level. Both the English and Spanish versions of our final booklet tested extremely well with our target audience in terms of interest, comprehension, and message resonance. This booklet has just been printed, and we have already had requests for this item throughout the country. This booklet appears to be an effective folic acid educational tool to reach an audience that might otherwise "fall through the cracks."

Conclusion: This folic acid educational material is unique in that it aims to reach an at-risk population, who may not have been touched by the current array of educational materials, with an important birth defects prevention message. This folic acid educational tool is a step toward establishing sensitivity to literacy when developing health communication strategies as outlined by the health literacy objective of Healthy People 2010. Most importantly however, this new material and others like it cannot fulfill their purpose without health professionals and birth defects prevention workers being aware of its availability and usefulness. Our hope is that our poster display will teach others the importance of literacy sensitivity, how professionals can become more literacy sensitive in their own work, and provide them a place to find high quality, effective, and free materials that utilize literacy sensitive principles.

C3.5. Epidemic Intelligence Service; Epidemiology Program Office¹ National Center on Birth Defects and Developmental Disabilities² (CDC)

An Evaluation of the Folic Acid Module in the Behavioral Risk Factor Surveillance System (BRFSS): Advantages, Disadvantages, and Recommendations

Kathleen Green Raleigh^{1,2}, Christine Prue², Joe Mulinare²

Objective: The objective of this evaluation was to review the usefulness, timeliness, quality, and cost of data obtained from the optional Behavioral Risk Factor Surveillance System (BRFSS) folic acid module (FAM) compared to a national survey of pre-pregnancy awareness conducted by the March of Dimes (MoD) in order to determine the most effective use of public health resources for the National Center on Birth Defects and Developmental Disabilities.

Methods: We interviewed representatives from state public health departments about their use and experience with the FAM. We conducted a cost analysis to compare BRFSS FAM with the MoD survey for collecting information from women of childbearing age about their folic acid knowledge and use.

Results: The FAM is currently used by 14 states to assess the prevalence of folic acid use and knowledge among childbearing age women. Unlike the FAM, the MoD is a national convenience sample and state-specific data is not provided. State program planners use the information from the FAM to assess changes and target education programs. However, states do not use the FAM consistently. Some states have reported an increased interval between data collection and the availability of final results, from 12-months to approximately 18-months, compared to MoD which reports results within 6 months of data collection. Information collected from BRFSS FAM and the MoD on folic acid usage is quite similar in both surveys. Reported folic acid knowledge, however, was higher among respondents of the BRFSS FAM. The National Chronic Disease Prevention and Health Promotions' new fee structure for administering the BRFSS FAM increased from \$75,000 in 2002 to \$175,000 for 2003 (costs incurred are based on the number of states using the module) compared to MoD costs of approximately \$98,000 for its national survey.

Conclusions: The BRFSS' greatest strength, providing useful state-level data, was confirmed by study participants. However, a number of limitations were revealed that make using the BRFSS FAM a less than optimal choice for states and NCBDDD: timeliness and cost respectively. States report an increased interval between data collection and data availability. In addition, states do not consistently use the BRFSS FAM. The cost to administer the BRFSS is more than the cost of the MoD. A more comprehensive evaluation should be conducted among BRFSS states to determine their reasons for choosing to use or not use the module.

C3.6. Folic Acid Campaign and Birth Defects Surveillance System Puerto Rico Department of Health

Evaluation and Changes of the Folic Acid Messages Used in Puerto Rico

Elia M. Correa, Diana Valencia, Hector I. García

Objective: To identify barriers in the population of Puerto Rico in the use of folic acid vitamin, and develop new campaign strategies to promote its use.

Methods: In collaboration with a market research company two studies were developed. One was a focus group and the other was a household survey. The focus group had a sample of 5 groups of females between 15 to 50 years old and one group of males between 19 to 50 years old. Four groups were from the metro area and two were done in the west and south area of the island. A guide was done including 30 questions. The household survey considered 725 subjects using a stratified sample by gender, age and geographic areas based on the 2000 US Census of population. 625 were females and 100 were done on males. A survey questionnaire was designed and 35 questions were included resulting from the input obtained from the focus group. The questions were about folic acid and vitamin awareness, knowledge and use, and eating habits.

Results: From the focus groups the general perception was that the folic acid vitamin was mainly emphasized for pregnant women and healthier babies. The survey revealed that most of the households interviewed (56%) believed that folic acid is only for women and it should be taken during pregnancy (54%) Half of the participants (47%) recalled the folic acid campaign. When asked about what they recalled from the media, they mentioned that its main benefit was having healthier babies (28%), that pregnant women was its main target (42%) and some of them did not recall the messages (10%) After reading a new folic acid message that includes the benefits for the population, most of them (87%) felt motivated to consume the folic acid vitamin and will recommend it to relatives and friends (67%) After taking the survey most of the participants (75%) declared that they will take the folic acid vitamin.

Conclusions: We have learned that a potential way to increase the use of folic acid in the population, that would be more appealing to women of reproductive age, is to encourage daily multivitamin consumption from an early age, and to include all benefits of the vitamin in the educational material, and thus we developed a new media campaign.

C3.7. Iowa Department of Public Health and the Iowa Birth Defects Registry

The Iowa Birth Defects Registry Parent Notification System: Six Months of Experience

Tammy O'Hollearn, Tonya Diehn, Paul Romitti, Kim Keppler-Noreuil

Objectives: To inform families in Iowa when their child has been placed on the Iowa Birth Defects Registry (IBDR) and to provide them with information about early intervention and supportive services for which they may be eligible.

Methods: The IBDR Parent Notification System was implemented in June 2003 in response to a recommendation of the State Genetics Plan for Iowa and subsequent Iowa Birth Defects Registry administrative rule mandate. A parent/professional work group and statewide parent focus groups developed a notification packet of informational materials for families including a notification letter, response card, frequently asked questions sheet about the Iowa Birth Defects Registry, and a resource brochure. Implementation, follow-up and tracking processes were established. The first letters were mailed in June, 2003. A notification packet is mailed to the family and a copy of the letter is provided to the physician of record. A follow-up call is provided two weeks after the packet is sent to assure that families have received the information, answer any questions, and make early intervention and supportive service referrals as needed. Parents send in a response card if they do not wish to receive the follow-up call.

Results: There were 506 parent notification packets mailed between June 19, 2003 and December 11, 2003. The average length of time for notification (babies date of birth to the date that the letter was mailed to the family) was 5.24 months. Of the 506 notification packets mailed, 65 families chose to opt out of the personal follow up call. Two families have been unlocatable. Seven families requested another form of communication (Spanish or Vietnamese). Referrals were made in four cases. Nine cases have been deleted from the Registry due to incorrect diagnosis and six cases are being reviewed to ensure that the diagnosis is correct. Birth defects ranged from minor to major such as syndactyly to spina bifida. Some of the most common birth defects were heart defects (I.e. ASD, VSD, etc), hypospadias, hip dislocation, pyloric stenosis, hydronephrosis, cleft lip and palate, and Down syndrome.

Conclusions: The IBDR Parent Notification System is improving the awareness of available early intervention and supportive services for families in Iowa and assisting in identification of children with special needs.

C3.8. March of Dimes Birth Defects Foundation

Health Care Professionals Knowledge and Practices Regarding Folic Acid

Stephen M. Abelman, Karla Damus, Jennifer Williams, Cheryl Stone

Objective: To determine awareness of, and response to, the USPHS folic acid recommendation among a national sample of physicians and mid-level providers

Method: A random sample telephone survey of 362 general Obstetrician-Gynecologists (OB/GYNs) and 249 Family Physicians (FPs) conducted between March and July 2002 and 200 Certified Nurse-Midwives (CNMs) and 300 other professionals (Nurse Practitioners, Physician Assistants and RNs) in June and July 2003.

Results: One-half (50%) of providers knew that approximately one-half of all pregnancies are unplanned. Ninety percent of providers recognized folic acid supplementation should begin at least a month before conception and 86% reported always recommending folic acid to women planning pregnancies. However, providers reported seeing less than 25% of prenatal patients preconceptionally. Only 24% of providers always recommended folic acid to non-pregnant women. Awareness of folic acid's benefits regarding some birth defects was very high (97%), although over one-half (53%) misstated the correct dose. Almost three-quarters (69%) misstated the correct dose for women with a previous NTD-affected pregnancy.

Conclusion: Knowledge about folic acid benefits was high among respondents, but more education about correct doses is needed. Promotion of folic acid was greatest for women contemplating pregnancy; however, respondents reported that few women receive preconceptional care. Folic acid use could increase and neural tube defects decrease if providers promoted the folic acid message to all women capable of having children at every available opportunity.

C3.9. The Michigan Birth Defects Registry (MBDR): Prevention, Monitoring and Follow-up

Michigan Children with Birth Defects: The Role of Hospitals in Linking Families with Services

Jane Simmermon, Lorrie Simmons, Janice Bach, Glenn Copeland

Objective: The primary purpose of the study was to determine the extent of referrals made by hospitals before discharge to information and services for children reported to the Michigan Birth Defects Registry (MBDR).

Methods: The MBDR Quality Analyst and Follow-up Coordinator visited 20 inpatient hospital medical record departments across the state to abstract the health records of 825 children randomly selected from MBDR case reports; all were born between 1997 and 2001. Activities included: 1) validating case diagnostics and 2) documenting referrals of the child and/or family to information and services [such as medical/surgical **inpatient** specialists, genetic counseling/testing, specialty **outpatient** clinics after discharge, and **public health** services such as Early On®, Children's Special Health Care Services (CSHCS) and the Women, Infants and Children (WIC) Program].

Results: Of the 825 health records reviewed, 699 (84.7%) children had one or more referrals to inpatient specialty care, outpatient specialty care or public health services. Referral to Early On® was present in 139 of 699 health records (19.9%); referral to CSHCS was present in 141 of 699 health records (20.2%); and referral to WIC was present in 72 of 699 health records (10.3%). Of the referrals documented, 60.2% originated from physicians, 17.5% originated from social workers and 19.1% originated from discharge planners. Regarding data quality, 85.6% of cases were reported to the MBDR with the correct diagnosis, 8.6% were false-positives, 2.8% were reported with an incorrect ICD-9 code, 2.1% had an additional condition that was not reported to the MBDR, and 1% were 'rule-out' conditions that should not have been reported at all.

Conclusions: Michigan children with birth defects who have been reported to the MBDR appear to be well linked with inpatient specialty care during their hospital stays. However, linkage to public health services such as Early On® and CSHCS was difficult to measure as evidenced by less documentation in the health record of **inpatient** referrals to these services. It is possible that additional referrals are occurring by a method that could not be measured in this study (e.g. undocumented referrals occurring in the hospital or through word-of-mouth). More likely linkage with services is occurring in **outpatient** settings after a child with birth defects is discharged from the hospital but we cannot use the MBDR to measure those events. A variety of referral practices were observed in different hospitals and will be used as a basis for formulating and disseminating "best practice" guidelines for linking children with birth defects to intervention services. The MBDR continues to have an important role in facilitating linkage to community-based services by collaborating on case finding activities with Early On® and CSHCS, as well as by providing resource materials to newborn nurseries, medical practices and educational outreach to social workers.

C3.10. New Mexico Birth Defects Surveillance and Prevention Program

Life Long Happiness: A Preconception Health Education Project Helping Women Make Healthy Choices

Maggi Gallaher, Jean Higgins

Objective: The New Mexico Birth Defects Prevention Task Force designed a preconception teaching tool that could be used to help women gain knowledge that would enable them to make healthy choices to prevent the occurrence of some birth defects. This project expanded on early studies that focused on Folic Acid intake. The goal of "Life Long Happiness: A Preconception Health Education Project" is to reduce the risk of birth defects through: increased awareness of the importance of folic acid intake, avoidance of tobacco, avoidance of alcohol and drugs, diagnosis and treatment of diabetes, and prevention of obesity through nutrition and exercise. The approach taken by the Task Force included utilization of Motivational Interviewing (MI) techniques to engage the clients more fully. They selected the title "Life Long Happiness" which is a concept of wellness arising from the Navajo culture, "Sa'ah Naaghai Bik'eh Hozhoon".

Method: A module was developed in Year 4, and a pilot project to test the effectiveness of the module is being conducted in Year 5 with plans to expand use of the module statewide during Year 6. The use of pre and posttests with a six week follow up posttest examines initial knowledge gain and retention. Analysis of results will aid in planning modifications prior to statewide deployment.

Results: Initial response from organizational staff using the module is extremely positive based on anecdotal reports of success. Data analysis indicates that there is a knowledge gain immediately after the intervention. Long-term retention results will be presented.

Conclusion: The module has been shown to be an effective teaching tool under a wide variety of presentations. The motivational Interviewing skills are more difficult to master than anticipated, however, early results indicate that there is knowledge gain even when the educator does not utilize the skills. The tests and the module will be presented along with available data analyses that are currently underway.

C3.11. New York State Congenital Malformations Registry

Follow-up Survey on Parents of Children with Major Birth Defects in New York State

Monica Sharpe-Stimac, Ying Wang, Charlotte M. Druschel, Philip K. Cross

Background and Objective: One of the objectives of New York State birth defect surveillance system, the New York State Congenital Malformations Registry (NYCMR), is to identify children with special needs and assist in evaluation of prevention/intervention programs and services. In 1999, the NYCMR started a statewide mass-mailing program to inform parents of children with major birth defects about programs and support groups that might be helpful to them. A follow-up survey was conducted by mail in the summer of 2002. The objective of this survey was to evaluate the usefulness of the mailing program.

Methods: The survey population consisted of parents who were contacted by mail between 9/10/2001 and 12/05/2001, and whose children were born in 2001 and had major birth defects. The survey questionnaire included a set of questions on the usefulness of the information sheets provided with the mailings. Two subsequent follow-up mailings were sent to parents who did not respond, within three to four weeks of each mailing. Parents who did not respond to any of the three mailings were contacted and interviewed by phone.

Results: Of the 286 families selected in the study, 43% (122) responded to the survey. About 66% of responding parents stated that the information provided by the mailing program was helpful, and 58% had contacted and/or used the programs and services provided in the information sheets. Parents with children younger than 6 months at the time of mailing were more likely to find the information helpful, compared to parents with older children (≥ 6 months). The majority of responding parents had contacted and/or used the Early Intervention Program. In addition, the current survey had obtained helpful feedback from responding parents about the mailing program administered by NYCMR since 1999.

Conclusions: The findings from the current survey show that the statewide information-mailing program administered by NYCMR is helpful and useful to the families of children with special needs. With regard to the parents' comments and suggestions, additional information and Internet sites specific to various birth defects and social and financial support are being reviewed for possible inclusion in the mailing package.

C3.12. North Carolina Birth Defects Monitoring Program

Association Between Maternity Care Coordination Services and Referral to the Child Service Coordination Program Among Infants with Craniofacial Anomalies

Cynthia Cassell, Robert Meyer, Fatma Simsek, and Anita Farel

Objective: To determine if the receipt of maternity care coordination (MCC) services increases the likelihood of referral to the Child Service Coordination Program (CSCP) among infants with craniofacial anomalies.

Methods: Using data from North Carolina Vital Statistics, the CSCP, and the North Carolina Birth Defects Monitoring Program for 1999-2000, we determined referral rates of infants to the CSCP among women who did and did not receive MCC services. Rates were compared in perinatal regions of residence, which were identified as Northwest, Northeast, Southwest, Southeast, Eastern, and Western. Rates were also determined for the following sociodemographic variables: marital status, number of living children, WIC status, Medicaid status, number of anomalies, hospital level of care at birth, and maternal age, education, and race/ethnicity.

Results: From a total of 336 mothers of infants with craniofacial anomalies, we found that 23.21% of women received MCC services whereas 76.79% did not receive such services. We also found that 58.93% of infants were referred to the CSCP whereas 41.07% were not referred. Of the infants who were referred to the CSCP, only 31.82% of women received MCC services. Of the infants who were not referred to the CSCP, 89.13% did not receive MCC services. Crude bivariate analysis indicated that among infants with craniofacial anomalies, the risk of being referred to the CSCP among those who received MCC services was 1.54 (95% confidence interval: 1.32, 1.81) times the risk of being referred to the CSCP among those who did not receive MCC services on the referral rate to the CSCP. Using multivariate analysis, we controlled for possible confounding variables to see if this risk changed.

Conclusions and Implications: Our analysis demonstrated that receipt of MCC services has a causative effect on referral to the CSCP. In addition, the majority of women did not receive MCC services. Future studies should examine the duration of MCC services and compare infant health outcomes among women who received MCC services and whose infants are referred to the CSCP.

C3.13. Recurrence Prevention Campaign

Spina Bifida Recurrence Prevention Efforts and Progress

Adriane K. Griffen

Objective: The Recurrence Prevention Campaign is a three-year national campaign which began in September 2002 to educate women at increased risk for neural tube defect (NTD)-affected pregnancies (specifically women who have a child with spina bifida, have spina bifida themselves, or have had an NTD-affected pregnancy) and their health care providers about the importance of increasing folic acid consumption by prescription prior to future pregnancies.

Methods: The Campaign works on a national level with a focus in three states with traditionally higher rates of spina bifida: AL, NC and TX. The Campaign works with SBAA chapters, spina bifida clinics, and partners on the National Council on Folic Acid and the private sector. Health education, media advocacy, and social marketing approaches guide outreach to local libraries, health departments, medical societies, banks and grocery stores; media outreach in target states; and development of a folic acid counseling tutorial, *Got a Minute?* (March 2003), based on formative audience research.

Results: SBAA's National Survey of the Spina Bifida Community examined provider counseling and awareness among women at increased risk for NTDs (t_1 February 2003, N=420, t_2 August 2003, N=267). Survey data were analyzed for the country as a whole due to low Ns in campaign target states. The survey found increased levels of folic acid counseling by providers (t_1 59%, t_2 63%), consumption (t_1 33% everyday, 15% < 7 days/wk; t_2 36% everyday, 18% <7days/wk), perception of folic acid effectiveness (t_1 15% very effective, t_2 19% very effective) and awareness of how much folic acid to take when planning a pregnancy (t_1 32%, t_2 39%). Process data show that folic acid is being mentioned to women and providers 57% more often by spina bifida clinics and local SBAA chapters. Media advocacy efforts to date have resulted in TV, radio and print placements reaching more than 2 million.

Conclusions: Sustainable awareness efforts are needed as most women at increased risk for NTDs are not aware of their need for prescription folic acid and are often not counseled by a health care professional.

C3.14. Texas Department of Health¹, Public Policy Research Institute² – TAMU

Birth Defects in the News: A Content Analysis of U.S. Daily Newspapers

Amy P. Case¹, Michael Voloudakis², Ann F. Phelps¹

Objective: The efficacy of health messages can be influenced by the perception of risk for a particular hazard or illness by the target population. Working from the hypothesis that popular print media may over-represent certain conditions while neglecting to cover more common conditions, this poster quantitatively analyzes coverage of birth defects in U.S. daily newspapers.

Methods: We performed a content analysis of articles that appeared between October 1, 2001 through September 30, 2003 in U.S. daily newspapers using EBSCO Newspaper Source. Keyword search terms and phrases were selected from the results of a previous review and included both the technical terms for selected conditions as well as popular variations and general categories. Articles were read and any reference to a birth defect was recorded exactly as described. Each recorded reference was then reviewed by surveillance staff and coded based upon the content of the article. We then analyzed: 1) Frequency with which a birth defect appeared in these newspapers relative to that defect's occurrence in the Texas Birth Defects Registry; 2) Type of story, or frame, in which the defect(s) was mentioned; 3) Mention of causes or risk factors, if any; and 4) Any mention of associated prevalence rates.

Results: More than 20 key words or phrases were used to yield a total of 381 unduplicated articles and 495 individual references to a birth defect. Forty percent (152) of these references used only a generic term such as "birth defect" or "deformities", without mentioning a specific defect. Neural tube defects were the most frequently featured, appearing 46 times; while heart, lung, and circulatory defects were mentioned 41 times. Conjoined twins, which are estimated to occur in only 1 in 75,000-100,000 live births, appeared in these articles 21 times. Less than 10% of the articles mentioned any type of rate. We will also present a summary of risk factors/causes and frames used.

Conclusions: Prospective parents may hold false assumptions about the risk of having a pregnancy affected by a specific birth defect if they are influenced by newspaper coverage. Public health officials should seek to ensure that reporters receive accurate information about the relative frequency of a particular defect and any known risk factors or causes.

Category 4: Program methodology – Advisory Committees, Legislation, Planning

C4.1. Minnesota Department of Health Birth Defects Prevention and Information Program

Comparison of Birth Defect Reporting Trends Between Passive and Active Case Ascertainment Methods at a Minneapolis Hospital

Myron Falken, Daniel Symonik, Richard Lussky, Nancy Mendelsohn, Maureen Alms, Emily Hansen

Objectives: This pilot study compared the number of birth defect cases identified by birth certificates, hospital discharge records, and active abstraction methods at the Hennepin County Medical Center (HCMC). Located in downtown Minneapolis, HCMC provides care for a very diverse ethnic population and records more than 400,000 patient visits annually. The main goals for the project were to evaluate active surveillance collection techniques for birth defects versus passive surveillance methods and to evaluate the performance of an active surveillance system in order to better identify needed resources.

Methods: The medical records for all births at HCMC between 1/1/01 and 12/31/01 (approximately 3000) were reviewed for 43 birth defects, as identified using ICD-9 codes and other key words. This included both paper and electronic records. Approvals from appropriate IRBs were obtained prior to starting the study. All records containing a birth defect or possible birth defect were further reviewed by a neonatologist (Dr. Lussky) or a medical geneticist (Dr. Mendelsohn) to ensure complete and accurate diagnosis and abstraction. Birth certificate and other passively collected information was obtained directly from the MDH Center for Health Statistics.

Results: Initial results clearly identify significant differences between medical records and passive data, which is consistent with current literature. While the predominant trend is towards under-reporting by passive sources, our findings also reflect over-reporting of birth defects in individual records. The most dramatic result reveals numerous children with heart defects in the medical records while the MDH birth certificates for the same period show none.

Conclusions: Examining records at HCMC has proven to be a valuable pilot for a future statewide birth defects program and has helped identify barriers, resources needed, and data collection protocols. It has also greatly improved our understanding of how medical records are generated and maintained. Ultimately, this information will assist MDH in establishing a more effective and comprehensive Minnesota Birth Defects Prevention and Information Program.

C4.2. Washington State Birth Defects Surveillance System

Accomplishments in Surveillance Revitalization, 2000 – 2003

Riley Peters, Jeanette Robbins, Civillia Winslow Hill

Objective: To provide an accounting (including timeline of events, impacts and results - including a Surveillance Report) of a concerted effort to reactivate a stimulated passive surveillance system in Washington State.

Method: Use the WA State Birth Defects Surveillance database and birth certificate information to illustrate participation rates for reporting facilities; and compare the passive reporting process (1995 - 1999) with the stimulated passive surveillance system (2000 - 2003). A timeline of administrative, legal and staff activities will show the impact of these activities in revitalizing the system beginning in 2000. Participation rates for both the number of facilities reporting as well as birth cohort coverage rates of reported cases will be provided. A listing of "What worked" and materials used will be also be included.

Results: Participation rose from 21 to 58 facilities and coverage rates rose from 42% to 84% over the course of 3 years. Reporting processes were also developed to facilitate reporting of "No Events" and web-based reporting of cases requiring secure transmission of PHI. These methods enhanced access and ease of reporting, ultimately providing more surveillance information.

Conclusions: A Surveillance Report for reporting facilities and for public health departments with inclusion of resources for both families and health professionals will publicize surveillance activities, increase reporting of birth defects and enhance community based prevention practices for birth defects and secondary disabilities, including community based care coordination for children and their families through public health nurses. The web-based system will be promoted. Lessons learned can be applied to next step in the state surveillance plan of reporting of autism, cerebral palsy and fetal alcohol syndrome.