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

C1.1 Arizona Birth Defects Monitoring Program
Changing Rate of Gastroschisis
Tim Flood, Viral Joshi, Christopher Tex

C1.2 Florida Birth Defects Registry
Contribution of Complementary Datasets
Roland Estrella, Rajeeb Das, Vivian Chang, Mario Ariet, Michael Resnick, and Jeffrey Roth

C1.3 Food and Drug Administration
Medical Product Exposure during Pregnancy: An Update on the OWH Pregnancy Exposure Registry Website
Pellavi Sharma, Ameeta Parekh, Elizabeth Duvall-Miller, Connie O'Leary, Kathleen Uhl

C1.4 Illinois Adverse Pregnancy Outcomes Reporting System
Can Vital Records Enhance a Passive Ascertainment Registry?
Jane Fornoff

C1.5 Iowa Registry for Congenital and Inherited Disorders
Family History Data Collection in the National Birth Defects Prevention Study: A Pilot Study
Paul A. Romitti, Kris K. Hardin, William T. Budelier, Charlotte M. Druschel, Charlotte A. Hobbs

C1.6 Iowa Registry for Congenital and Inherited Disorders
Urban-Rural Comparison of Characteristics of Stillbirths in Iowa
Paul A Romitti, Jennifer A Alm, William T Budelier, Bradley M McDowell, and Kimberly Piper

C1.7 National Center on Birth Defects and Developmental Disabilities, CDC
Impact of Prenatal Diagnosis on the Prevalence of Selected Non-NTD Central Nervous System Defects, Atlanta, 1994–2004
Assia Miller and Janet Cragan

C1.8 National Center on Birth Defects and Developmental Disabilities, CDC
The Importance of Nomenclature for Congenital Heart Disease: Implications for Research and Evaluation
M Strickland, T Riehle-Colarusso, J Jacobs, M Reller, W Mahle, L Botto, P Tolbert, M Jacobs, F Lacour-Gayet, C Tchervenkov, C Mavroudis, A Correa

C1.9 New Jersey Birth Defects Monitoring Program
Trends in Birth Defect Registry-Birth Certificate Matching: The New Jersey Experience
Donald C. Finn and Leslie M. Beres-Sochka

C1.10 New York State Congenital Malformations Registry
Development of Web-based Geocoding Applications for the Birth Defects Surveillance System in New York State
Ying Wang, Linh H Le, Xiaohang Wang, Anna Veksler, Zhen Tao, Philip K Cross

C1.11 New York State Congenital Malformations Registry
Evaluating Hospital Discharge Data as a Source of Case Ascertainment for Population-Based Birth Defects Surveillance Programs
Ying Wang, Philip K Cross

C1.12 Texas Birth Defects Epidemiology and Surveillance
Improving Data Quality Using Random Review of Birth Defect Coding
Ann Phelps

C1.13 Utah Birth Defect Network
Prenatal Diagnosis and Asertainment of Orofacial Clefts in Utah 1995-2005
Miland Palmer, Marcia L. Feldkamp, and John C. Carey

C1.14 Vermont Birth Information Network
Passive Case Ascertainment: An Evaluation of Data Sources
Peggy Brozicevic, John Burley and Leah Burke

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

C2.1 Department of Defense Birth and Infant Health Registry
Hemangiomas and Associated Birth Defects among Infants Born to U.S. Military Families
Anna T Bukowinski, Margaret A K Ryan, Donald J Slymen, Carter J Sevick, and Tyler C Smith

C2.2 Department of Defense Birth and Infant Health Registry
Does Smallpox Vaccine Impact the Reproductive Health of Service Members? Evaluations of Infertility, Adverse Pregnancy Outcomes, and Birth Defects
GR Gumbs, AMS Conlin, IG Jacobson, CJ Sevick, KJ Snell, TC Smith, and MAK Ryan

C2.3 Georgia Birth Defects Reporting and Information System
Neighborhood and Individual Characteristics as Predictors for Birth Defects in Metropolitan Atlanta, Georgia, 1994-2005
Jennifer C. Smith and Debra L. Thompson

C2.4 National Birth Defects Prevention Study
Maternal Thyroid Disease and Cardiovascular Malformations
M Browne, A Caton, S Rasmussen, C Druschel, A Lin, M Canfield, P Romitti

C2.5 National Center on Birth Defects and Developmental Disabilities, CDC
Herbal Use Before and During Pregnancy
Cheryl S. Broussard, Carol Louik, Margaret A. Honein, Allen Mitchell, and the National Birth Defects Prevention Study

C2.6 National Center on Birth Defects and Developmental Disabilities, CDC
Maternal Caffeine Intake during Pregnancy and Risk of Orofacial Clefts
SA Collier, ML Browne**,** MA Honein, SA Rasmussen, and the National Birth Defects Prevention Study

C2.7 National Center on Birth Defects and Developmental Disabilities, CDC
Maternal Prepregnancy Body Mass Index and Congenital Heart Defects: Results from the National Birth Defects Prevention Study, 1997-2003
A Correa, SM Gilboa, LM Besser, LD Botto, SA Rasmussen, DK Waller, M Cleves, CA Hobbs, T Riehle-Colarusso, and the National Birth Defects Prevention Study

C2.8 New York State Congenital Malformations Registry
Air Pollutants and Birth Defects in New York State
Erin Bell, Lei Chen, Alissa Caton, Charlotte Druschel, and Shao Lin

C2.9 New York State Congenital Malformations Registry
Congenital Malformations, Low Birth Weight, and Small for Gestational Age in a Community Affected by Soil Vapor Intrusion
Alissa Caton, Steve Forand, Elizabeth Lewis-Michl, Karen Nolan

C2.10 New York State Department of Health
Maternal Asthma, Asthma Medication Use and the Risk of Congenital Heart Defects
Shao Lin, Michele Herdt-Losavio, Lenore Gensburg, Elizabeth Marshall, Charlotte Druschel

C2.11 Oklahoma Birth Defects Registry
Exploring the Dataset on Selective Serotonin Reuptake Inhibitors (SSRIs) Drugs among Mothers of Infants in the Oklahoma Birth Defects Registry, 1994-2005
Elizabeth Kruger and Kay Pearson

C2.12 Rhode Island Birth Defects Program
Examining the Association between Maternal Risks and Birth Defects in Rhode Island, 2002-2006
William Arias and Samara Viner-Brown

C2.13 Texas Birth Defects Epidemiology and Surveillance Branch/Texas Center BDRP
Are Less Acculturated Hispanic Parents at Higher Risk for Having Offspring with Anencephaly and Spina Bifida?
MA Canfield, T Ramadhani , GM Shaw, DK Waller, SL Carmichael, B Mosley, R Olney, and the National Birth Defects Prevention Study (NBDPS)

C2.14 Texas Birth Defects and Epidemiology Branch/Texas Center BDRP
Birth Defects in Hispanics: Are they Related to Mothers' Birthplace?
Tunu Ramadhani, Vanessa Short, Mark A. Canfield, D. Kim Waller, Marjorie Royle, Adolfo Correa, Angela Scheuerle, and the National Birth Defects Prevention Study

C2.15 Texas Birth Defects Epidemiology and Surveillance Branch/Texas Center BDRP
Variation in pregnancy-related risk behaviors and maternal conditions among United States and foreign born mothers by race/ethnicity
Tunu Ramadhani, Mark A. Canfield, D. Kim Waller, Marjorie Royle, Adolfo Correa, and the National Birth Defects Prevention Study (NBDPS)

C2.16 University of South Florida Birth Defects Surveillance Program
Are Hispanics at Increased Risk of Gastroschisis?
Marie G. Pierre, Jennifer L. Kornosky, Jason L. Salemi, Kimberlea W. Hauser, and Jane D. Carver

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

C3.1 Arkansas Center for Birth Defects Research and Prevention
Gastroschisis and Mode of Delivery: National Trends and Evaluation of Outcomes, 1991-2005
T. M. Bird, J. M. Robbins, E. R. Kokoska, M. A. Cleves, J. A. Reading, C. A. Hobbs

C3.2 Department of Defense Birth and Infant Health Registry
Health Outcomes among Infants Born to Women Deployed in Support of the Wars in Iraq and Afghanistan
Isabel G. Jacobson, Carter J. Sevick, Tyler C. Smith, Gia R. Gumbs, Ava Marie S. Conlin, and Margaret A.K. Ryan

C3.3 Florida Birth Defects Registry
Risk of Preterm Birth for Black and Hispanic Infants with Major Congenital Heart Defects
Wendy N. Nembhard, Jason L. Salemi, Melissa L. Loscalzo, Tao Wang, and Kimberlea W. Hauser

C3.4 Hawaii Birth Defects Program
Descriptive Epidemiology of Bilateral Renal Agenesis and Dysplasia, Hawaii, 1986-2003
Mathias B. Forrester and Ruth D. Merz

C3.5 National Birth Defects Prevention Network
Geocoding Capacity of Birth Defects Programs: Results from the National Birth Defects Prevention Network (NBDPN) Geocoding Survey
Leslie O'Leary, Ying Wang, Russel Rickard, Craig Mason

C3.6 National Center on Birth Defects and Developmental Disabilities, CDC
Requirements for Reliable Estimation of Prevalence of Birth Defects
CJ Alverson, Cara Mai, and Adolfo Correa

C3.7 National Center on Birth Defects and Developmental Disabilities, CDC
Is Prior Pregnancy Loss Associated with an Increased Risk for Birth Defects?
James E Kucik, CJ Alverson, Adolfo Correa

C3.8 National Center on Birth Defects and Developmental Disabilities, CDC
Survival of Infants with Down syndrome in Ten Regions of the United States
Chengxing Lu, Mikyong Shin, Csaba Siffel, James E. Kucik, Lisa K. Marengo, Adolfo Correa, and the Congenital Anomaly Multistate Prevalence and Survival (CAMPS) Collaborative

C3.9 National Center for Birth Defects and Developmental Disabilities, CDC
Long-Term Survival of Infants with Atrioventricular Septal Defects with and without Down Syndrome in Atlanta
Assia Miller, Csaba Siffel, Chengxing Lu, Tiffany Riehle-Colarusso, Adolfo Correa

C3.10 National Center on Birth Defects and Developmental Disorders, CDC
Effectiveness of National Death Index for Ascertainment of Infants and Children: Example of Atlanta Spina Bifida and Down Syndrome Deaths
R Miller, L. Besser, A Correa

C3.11 National Center on Birth Defects and Developmental Disabilities, CDC
Prevalence of Major Birth Defects in Metropolitan Atlanta, 1978-2003
Lisa Rynn, Janet Cragan, Adolfo Correa

C3.12 National Center on Birth Defects and Developmental Disabilities, CDC
Down Syndrome Prevalence among Children in Ten Regions of the United States
M Shin, J Kucik, C Lu, C Siffel, and A Correa

C3.13 National Center on Birth Defects and Developmental Disabilities, CDC
Spina Bifida Prevalence among Children in Ten Regions of the United States
M Shin, J Kucik, C Lu, C Siffel, and A Correa

C3.14 National Center on Birth Defects and Developmental Disabilities, CDC
Improving Survival of Infants with Biliary Atresia in Atlanta
Csaba Siffel, Chengxing Lu, Assia Miller, Richard Olney, and Adolfo Correa

C3.15 National Center on Birth Defects and Developmental Disabilities and Michigan Birth Defects Registry
Birth Defects and Genetic Disorders among Arab Americans—Michigan, 1992–2003
Emad Yanni, Glenn Copeland, Richard Olney

C3.16 New York State Congenital Malformations Registry
Prevalence of Selected Birth Defects in New York State, 1999-2004
Ying Wang, Charlotte M. Druschel, Philip K. Cross

C3.17 North Carolina Birth Defects Monitoring Program and North Carolina Folic Acid Campaign
Prevalence of neural tube defects in North Carolina, 1995/1996 to 2004/2005
Amy Mullenix, Jennifer Stock, Robert E. Meyer

C3.18 Seoul National University Hospital
Discordant Newborns have a Higher Rate of Major Anomalies than Concordant ones in Dichorionic Twins
Kyung Joon Oh, Jong Kwan Jun

C3.19 Texas Birth Defects Epidemiology and Surveillance Branch
Impact of Differing Texas-Mexico Border Definitions on Birth Defect Prevalence, 1999-2004
Mark Canfield, Lisa Marengo, Amy Case

C3.20 Washington Birth Defects Surveillance System
Gastroschisis Cluster Investigation in Southwest Washington, July 2005 to April 2007
Katherine Hutchinson and Cathy Wasserman

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

C4.1 Colorado Responds to Children with Special Needs
Knowledge and Consumption of Folic Acid Working to Reduce Neural Tube Defects in Colorado
Kirk Bol, Rickey Tolliver, April Montgomery, Russel Rickard

C4.2 National Center on Birth Defects and Developmental Disabilities, CDC
Health Care Expenditures of Medicaid-Enrolled Children with Spina Bifida
Djesika Amendah, Scott Grosse, Lijing Ouyang

C4.3 National Center on Birth Defects and Developmental Disabilities, CDC
Linking Children with a Fetal Alcohol Spectrum Disorder to Services: State Based Strategies, Challenges, and Successes
FASD Prevention Project Sites, April Montgomery, and Jacquelyn Bertrand

C4.4 National Center on Birth Defects and Developmental Disabilities, CDC
Effectively Communicating the Folic Acid Message: Findings from Formative Research with Spanish-speaking Latinas
Alina L. Flores, Christine E. Prue

C4.5 National Center on Birth Defects and Developmental Disabilities, CDC
Birth Defects: What's in a Name?
Cara T. Mai, Assia Miller

C4.6 New Hampshire Birth Conditions Program
Folic Acid Knowledge, Behaviors & Beliefs: A Multivitamin Distribution Campaign in New Hampshire
Lissa Sirois, Stephanie Miller, Lisa Richards, John Moeschler

C4.7 New York State Congenital Malformations Registry
Folic Acid Awareness and Use in New York State, 1997 - 2006
April A. Austin, John F. Oldi, Charlotte M. Druschel

C4.8 New York State Congenital Malformations Registry, Iowa Birth Defects Registry
Arkansas Center for Birth Defects Research and Prevention, National Foundation for Facial Reconstruction
Organized Team Care and Services Received by Children with Oral Clefts
April A. Austin, Charlotte M. Druschel, Margaret Tyler, Paul A. Romitti, James M. Robbins, Whitney Burnett, Sara Kizelnik-Freilich, Peter Damiano

C4.9 North Carolina Birth Defects Monitoring Program and University of NC Craniofacial Center
Parental Perspectives on Barriers to Care among Children with Orofacial Clefts
Cynthia H. Cassell, Dara Mendez, Ronald P. Strauss, Vanessa White, and Robert Meyer

C4.10 Puerto Rico Birth Defects Surveillance System
Women Reactions to the Puerto Rico Folic Acid Campaign
Diana Valencia and Laureane Alvelo-Maldonado

C4.11 Utah Birth Defect Network
WIC Vitamin Pilot Project to Enhance Folic Education in Utah, 2000-2003
Amy E. Nance, Marcia L. Feldkamp

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

C1.1 Arizona Birth Defects Monitoring Program (ABDMP)

Changing Rate of Gastroschisis

Tim Flood, Viral Joshi, Christopher Tex

Background: The Arizona Department of Health Services has received requests for definitive information concerning the rate of gastroschisis. In this project we ask whether the rate of gastroschisis is increasing statewide and whether demographic issues such as ethnicity and maternal age may play a role.

Method: From 1986 to the present time, the ABDMP has registered the count of infants diagnosed with various birth defects, including gastroschisis. Also, cases of omphalocele have been included among the cases ascertained by the ABDMP. Cases that are live born or stillborn are registered into the ABDMP. To address the concerns about rates, we queried the databases of the ABDMP for cases of gastroschisis (756.710-756.719), and omphalocele (756.700-756.709) as a quality control measure. We used these counts to generate the prevalence rate of these two conditions, by year, ethnicity, and maternal age, for births occurring in Arizona.

Result: Between 1986 and 2004 there were 547 gastroschisis cases (live [503] or stillborn [44]) diagnosed among women who gave birth in Arizona. The prevalence rate of gastroschisis over the entire period was 3.8 cases (live or stillborn) per 10,000 live births. Analysis of the temporal trend of gastroschisis shows a non statistically significant increase in the trend of the rate (slope of the trend is +1.8; p=0.17). However, using data from 1986-1990 as a baseline (2.9 cases per 10,000 births), the rate of gastroschisis is statistically significantly elevated in six of the fifteen years since 1991. When analyzed by age of the mother, the gastroschisis rate (1989-2004) was generally highest among mothers in the 15-19 year old age group (9.2 cases per 10,000 births). The trend of the gastroschisis rate for this youngest age group generally has increased since 1989 (slope of trend is +0.75; p=0.01) In contrast, the prevalence rate of omphalocele over the entire period was 1.9 cases (live or still born) per 10,000 live births and has shown little change over time (slope of trend -3.95; p=0.05).

Conclusions: For combined maternal ages, our data suggest no significant trend in the prevalence rate of gastroschisis, but a statistically elevated rate in six of the years. The trend of the rate in women age 15-19 has generally increased during the past 15 years.

C1.2 Florida Birth Defects Registry

Contribution of Complementary Datasets

Roland Estrella, Rajeeb Das, Vivian Chang, Mario Ariet, Michael Resnick, and Jeffrey Roth

Background: The Florida Birth Defects registry is constructed by merging records from five datasets: Hospital Inpatient Discharge (Birth and Rehospitalization), Hospital Ambulatory Outpatient, Part C Program, Regional Perinatal Intensive Care Centers (RPICC), and Children Medical Services' subspecialty clinics to Birth Vital Statistics. Although approximately 94% of children with Birth Defects are found by linking Hospital Discharge to Birth Vital Statistics, the remaining four datasets make significant contributions at the individual reportable Birth Defect category level. These complementary datasets contribute to the Birth Defect Registry in two ways: first they help identify children with Birth Defects that cannot be linked from Hospital Discharge due to insufficient linking information, and second, with the exception of RPICC, they provide detection of CDC reportable Birth Defects within the infants' first year of life which were not identified at birth and for whom rehospitalization did not occur.

Methods: Using Florida Birth Defect Registry output datasets and Microsoft SQL Server reporting services, the contribution from each of the five merged datasets that form the registry was summarized by CDC Birth Defect reportable category for children born in years 2003 and 2004. The analysis presents the proportion of Birth Defects found in Hospital Discharge and in a given complementary dataset by CDC reportable category and the proportion of Birth Defects found *only* in a given dataset by CDC reportable category.

Results: The Hospital Discharge data source provided 94% (2003) and 93% (2004) of children with Birth Defects. All datasets other than Hospital Discharge provided more than 10% of the Birth Defects in year 2003 for 19 out of 42 categories and in year 2004 for 26 out of 42 categories. All datasets other than Hospital Discharge provided more than 20% of the Birth Defects in year 2003 for 8 out of 42 categories and in year 2004 for 11 out of 42 categories.

Conclusions: Using only Birth Hospital Discharge and Rehospitalization data limits the reporting of Birth Defects particularly at the CDC reportable category level. Three of the four complementary non-Hospital Discharge datasets (Hospital Ambulatory Outpatient, Part C Program, and Children Medical Services' subspecialty clinics) contribute significantly to the number of Birth Defects found in a subset of CDC reportable categories. These datasets also complement the Hospital Discharge data source for those children who could not be identified by Birth Vital Statistics due to insufficient linking information. New probabilistic merging techniques may be able to enhance the find rate within Hospital Discharge Birth and Rehospitalization. However, they will not replace the capacity of the complementary datasets to identify children with Birth Defects that are not detected at birth and who are not rehospitalized during their first year of life. Birth Defects Registry research should focus on the similarities and differences in CDC reportable Birth Defects categories based on those identified at birth and those identified within the first year of life.

C1.3 Food and Drug Administration

Medical Product Exposure during Pregnancy: An Update on the OWH Pregnancy Exposure Registry Website

Pellavi Sharma, Ameeta Parekh, Elizabeth Duvall-Miller, Connie O'Leary, Kathleen Uhl

Objective: With approximately 50 percent of pregnancies unplanned in the United States, many women unwittingly expose their fetus to medication, possibly affecting its health. In 2002, lack of data regarding the effects of medical products on the fetal health prompted the Food and Drug Administration (FDA) to issue a guidance regarding the design and merits of a pregnancy exposure registry. The guidance defines a pregnancy exposure registry as a prospective observational study that collects health information on the woman and her fetus throughout the pregnancy, while both are exposed to a drug or biologic product (e.g. anti-retroviral medication or vaccine). In May 2002, the FDA Office of Women's Health (OWH) created a web listing of pregnancy exposure registries available for drug or biologic products. OWH provided a centralized web listing in order to provide pregnant women with information about specific studies underway and to potentially facilitate their enrollment into a registry. The current project undertaken was to collect information on currently enrolling pregnancy exposure registries since issuance of the guidance and to enable its public access.

Methods: Internal FDA Center for Drug Evaluation and Research (CDER) and the Center for Biologic Evaluation and Research (CBER) databases were searched for products that required a pregnancy exposure registry as a post-marketing commitment or Phase 4 study.
A total of 41 products were found. Seventeen were already listed, one product was withdrawn from the market, and one product was released from the requirement. The 17 registries already listed on the original site were first contacted for updated information. Through multiple mechanisms the remaining 22 registries were researched. Nine out of the 22 registries had unobtainable information and four registries no longer enrolling were removed.

Results: Thirteen new registries were added in December 2006. After this update, further queries of CDER and CBER databases in the following months, found five more required pregnancy exposure registries. The original web listing had 23 registries; eight specific to a medical condition (e.g. asthma) and 17 specific to a drug or biologic product. Currently the OWH web listing contains information about 37 pregnancy exposure registries; six specific to a medical condition, 31 specific to a medical product.

Conclusion: This web listing will serve as a resource for pregnant women and their clinicians using medical products. The need for a pregnancy exposure registry increases when there is potential for harm due to in utero exposure. Results of these studies can be used in preconception care. It is important for this useful information to be disseminated to patients and health care providers in a centralized manner. This research updates the centralized web listing. By acknowledging that many pregnant women will take and developing fetuses will be exposed to drugs or biologics during their pregnancy, the FDA has encouraged more research and discussion on this topic.

C1.4 Illinois Adverse Pregnancy Outcomes Reporting System

Can Vital Records Enhance a Passive Ascertainment Registry?

Jane Fornoff

Background: A successful registry will use multiple sources of information to identify as many cases as possible. The Adverse Pregnancy Outcome Reporting System (APORS) program's primary sources of birth defect cases are hospital reporting and fetal death certificates. Such passive case ascertainment methods are known to result in a lower number of identified cases than more active methods. By supplementing passive reporting with additional sources, it is possible to increase the number of cases identified. APORS recently obtained permission to use birth and death certificates to enhance case ascertainment. Generally, vital records are not considered reliable, but APORS staff was interested to determine whether these records could add useful information to Illinois's birth defect registry.

Methods: Children with specific birth defects recorded on their birth or death certificates were selected. The birth defects included: anencephaly, spina bifida, hydrocephaly, microcephaly, rectal atresia/stenosis, tracheoespophageal fistula/esophageal atresia, omphalocele/gastroschisis, renal agenesis and diaphragmatic hernia. Other specified, but more frequently occurring birth defects (cleft lip/palate, polydactyly/syndactyly/adactyly and Down syndrome) were not included because of staff time constraints).

These records were matched to APORS to determine how many cases had already been reported, and how many had been additionally identified through chart review as part of the program's active case verification. Cases that had not already been identified were scheduled for chart review to determine whether they were missed cases or whether the vital record was inaccurate.

Results: Most of the birth defects reported on the birth certificate had been identified by APORS, either through hospital reporting or case verification. However, there was significant variation in the proportion of cases that had been identified by type of birth defect. Only 31 percent of the children with spina bifida recorded on the birth or death certificate had been reported to APORS; while all the children with rectal atresia or stenosis recorded on either certificate had been reported to APORS.

Chart review for anencephaly is complete; of the 35 cases with anencephaly reported on the birth or death certificate, 26 had already been identified by APORS, an additional six were added; two were not cases and one was an out of state birth who could not be traced. Adding these six cases increased the number of anencephaly cases to 31, a 24 percent increase. Similar chart reviews are underway for the other birth defects; these results will be presented at the conference.

Conclusions: While birth and death certificates are neither sufficiently complete nor accurate to use as the foundation for a birth defect registry, they can be a useful tool for identifying charts for review. Not all conditions may be equally useful; since there are limits to staff availability, review of charts with vital record reports of either anencephaly or spina bifida may provide the biggest impact.

C1.5 Iowa Registry for Congenital and Inherited Disorders

Family History Data Collection in the National Birth Defects Prevention Study: A Pilot Study

Paul A. Romitti, Kris K. Hardin, William T. Budelier, Charlotte M. Druschel, Charlotte A. Hobbs

Background: Accurate knowledge of birth defects among relatives allows for improved risk assessment and reproductive planning for parents. Such knowledge can also serve as motivation to adhere to healthy behaviors, such as folic acid use or smoking cessation. To date, little published evidence exists regarding the knowledge and accuracy of maternal reports of birth defect occurrence among relatives. Using a comprehensive, self-administered family history questionnaire (FHQ) and birth defects surveillance data, we explored the quality of family history reports of birth defects provided by mothers enrolled in the National Birth Defects Prevention Study (NBDPS).

Methods: A pilot study was conducted at 3 NBDPS centers – Arkansas (AR), Iowa (IA) and New York (NY) – to collect maternal reports of family history of birth defects. Eligible subjects were mothers who had completed the NBDPS interview and had a child diagnosed with a cleft lip ± cleft palate delivered on or after January 1, 1998. Mothers were sent a FHQ with the NBDPS buccal swab kit. No additional incentive was initially included, although an additional $20 incentive was added more recently for buccal sample collection in AR and NY. To explore the feasibility of using a FHQ in the NBDPS, participation rates for buccal sample collection were calculated with and without inclusion of the FHQ. Also, maternal evaluations of FHQ items and layout of the FHQ were examined. To evaluate the quality of maternal reports of family history of birth defects at one site (IA), we compared IA FHQ reports of birth defects for offspring with state surveillance data.

Results: Participation rates for collection of FHQs were similar in AR and IA, but lower in NY. For all centers, participation rates for buccal sample collection were higher with than without a FHQ and were further increased with use of an additional incentive for buccal sample collection. Only a small number of mothers had difficulty understanding an FHQ item or deciding on a response; most indecisions were unknown birth dates. About one-half of mothers used assistance from a family member or health care professional to complete the FHQ, and most mothers rated the layout of the FHQ as 'good' or 'excellent.' Using Iowa surveillance data as a "gold standard," sensitivity of maternal FHQ responses was high for live birth status for case children and siblings, but differed for orofacial cleft type. Also, sensitivity of maternal FHQ responses was lower for reports of all other major defects diagnosed for case children and siblings. Specificity of maternal FHQ responses for case children and siblings was high.

Conclusions: Collection of detailed family history information in the NBDPS is feasible using a self-administered FHQ. Maternal evaluations of FHQ used to revise FHQ layout and selected item foils to provide more systematic collection of reports of other major structural birth defects. Future studies will expand comparison of questionnaire and interview reports in AR and NY and questionnaire and surveillance data in these centers.

C1.6 Iowa Registry for Congenital and Inherited Disorders

Urban-Rural Comparison of Characteristics of Stillbirths in Iowa

Paul A Romitti, Jennifer A Alm, William T Budelier, Bradley M McDowell, and Kimberly Piper

Background: In Iowa, stillbirths occur in about 1 in 200 deliveries; however, until recently, little study has been devoted to characterizing these outcomes. Using the pilot surveillance program for stillbirths in Iowa, we examined whether there are differences in clinical and parental characteristics of stillbirths by urban and rural residence in Iowa.

Methods: Beginning in 2005, the Iowa Registry for Congenital and Inherited Disorders developed and piloted methods for stillbirth surveillance using deliveries reported between January 1, 2000 and December 31, 2004. Case finding was initially conducted using fetal death certificates, and hospital records were subsequently reviewed to confirm that a stillbirth reached a gestational age of 20 weeks or greater and/or a delivery weight of 350 grams or more. Reported stillbirths determined to have resulted from elective terminations were excluded. For eligible stillbirths, maternal residence at delivery was coded as urban, large rural town, small rural town and isolated small rural town based. Frequencies and percentages of selected clinical and parental characteristics were calculated by type of residence and the magnitude of the differences between each type of residence was calculated.

Results: Hospital record review produced 916 eligible stillbirths. Maternal residence for these deliveries was distributed as follows: 528 (58.1%) as urban, 130 (14.3%) as large rural town, 130 (14.3%) as small rural town, 121 (13.3%) as isolated rural town; data for residences of 7 mothers could not be assigned to a residence type. Examination of clinical and parental characteristics showed that there was an excess of males for each type of residence. Maternal behaviors tended to be similar, but maternal and paternal age, race and ethnicity, and education differed among types of residence. Further, when stratified by gestational age categories, the average number of prenatal care visits differed for small rural town residents and isolated rural town residents for stillbirths occurring between 28 and 36 weeks compared to urban residents.

Conclusions: Given the prevalence of stillbirths in Iowa, comprehensive, population-based surveillance permits improved identification and monitoring of stillbirths and investigation of clinical and parental characteristics associated with these outcomes. Because of the rather large proportion of rural residents in Iowa, improved understanding of urban-rural characteristics of stillbirths, particularly prenatal care received, will aid in improving prevention efforts.

C1.7 National Center on Birth Defects and Developmental Disabilities, CDC

Impact of Prenatal Diagnosis on the Prevalence of Selected Non-NTD Central Nervous System Defects, Atlanta, 1994–2004

Assia Miller and Janet Cragan

Objective: In recent years, prenatal diagnosis and subsequent elective pregnancy termination has impacted the prevalence of neural tube defects (NTDs) significantly. However, the effect on the prevalence of other central nervous system (CNS) defects has not been thoroughly evaluated. We used data from the Metropolitan Atlanta Congenital Defects Program (MACDP) to examine the impact of ascertainment from prenatal diagnostic sources on the prevalence of non-NTD CNS defects in Atlanta from 1994 to 2004.

Methods: MACDP is a hospital-based surveillance for birth defects among infants and fetuses of at least 20 weeks gestation born to residents of the five central counties of metropolitan Atlanta. In 1994, out-patient prenatal diagnostic sites were added as an ascertainment source and the surveillance was expanded to include pregnancies electively terminated at any gestational age after prenatal diagnosis. We identified all CNS defects ascertained by MACDP from prenatal sources alone between 1994 and 2004. We excluded those for which an NTD was the only CNS abnormality and those for which the prenatal diagnosis was not definite. We then described each defect group by pregnancy outcome and presence of a known chromosomal abnormality, and calculated the change in prevalence when cases from prenatal sources were included. For the denominator, we used the number of live births to residents of the five central MACDP counties from Georgia birth certificates.

Results: A total of 48 pregnancies with a non-NTD CNS defect were identified from prenatal sources only. Among the 24 with holoprosencephaly, 6 (25%) resulted in stillbirth and 16 (67%) in elective termination. For 2 (8.3 %), the outcome was unknown. Among 12 with hydrocephalus, 1 (8%) resulted in live birth, 1 (8%) in stillbirth, and 10 (83 %) in elective termination. Among 5 with other types of cerebral reduction defects, 2 (40%) resulted in live birth and 1 (20%) in elective termination. For 2 (40%) pregnancies, the outcome was unknown. All 3 pregnancies with Dandy-Walker malformation and the 2 with other cerebellar abnormalities resulted in elective termination. A chromosomal abnormality was documented in 12 (50%) of those with holoprosencephaly, 2 (17 %) with hydrocephalus, and 1 (50%) with other cerebellar abnormalities. None of those with other cerebral reduction defects or Dandy-Walker malformation had a known chromosomal abnormality. When diagnoses from prenatal sources were included, the prevalence of holoprosencephaly increased 55% from 0.86 to 1.33 per 10,000 live births; that of hydrocephalus increased 6% from 4.11 to 4.35 per 10,000; that of other cerebral reduction defects increased 29% from 0.35 to 0.45 per 10,000; that of Dandy-Walker malformation increased 4% from 1.66 to 1.72 per 10,000; and that of other cerebellar abnormalities increased 5% from 0.84 to 0.88 per 10,000.

Conclusions: Between 1994 and 2004, outpatient prenatal diagnostic sites were an important MACDP ascertainment source for non-NTD CNS defects. Inclusion of diagnoses from these sources mostly impacted the prevalence of holoprosencephaly and other cerebral reduction defects. Inclusion of cases from prenatal sources is critical for population-based surveillance for major cerebral defects.

Disclaimer: The findings and conclusions in this presentation are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention.

C1.8 National Center on Birth Defects and Developmental Disabilities, CDC

The Importance of Nomenclature for Congenital Heart Disease: Implications for Research and Evaluation

M Strickland, T Riehle-Colarusso, J Jacobs, M Reller, W Mahle, L Botto, P Tolbert, M Jacobs, F Lacour-Gayet, C Tchervenkov, C Mavroudis, A Correa

Background: Administrative databases are often used for congenital heart disease research and evaluation, with little validation of the accuracy of the diagnostic codes.

Methods: Metropolitan Atlanta Congenital Defects Program surveillance records were reviewed and classified using a version of the International Pediatric and Congenital Cardiac Code. Using this clinical nomenclature as the referent, we report the sensitivity and false positive fraction (1 – positive predictive value) of the International Classification of Diseases, Ninth Revision, Clinical Modification diagnosis codes for tetralogy of Fallot, transposition of the great arteries, and hypoplastic left heart syndrome.

Results: We identified 4918 infants and foetuses with congenital heart disease from the surveillance records. Using only the International Classification of Diseases diagnosis codes, there were 280 records with tetralogy, 317 records with transposition, and 192 records with hypoplastic left heart syndrome. Based on the International Pediatric and Congenital Cardiac Code, 330 records were classified as tetralogy, 163 records as transposition, and 179 records as hypoplastic left heart syndrome. The sensitivity of International Classification of Diseases diagnosis codes was 83% for tetralogy, 100% for transposition, and 95% for hypoplastic left heart syndrome. The false positive fraction was 2% for tetralogy, 49% for transposition, and 11% for hypoplastic left heart syndrome.

Conclusions: Analyses based on International Classification of Diseases diagnosis codes may have substantial misclassification of congenital heart disease. Isolating the major defect is difficult, and certain codes do not differentiate between variants that are clinically and developmentally different.

Disclaimer: The findings and conclusions in this presentation are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention.

C1.9 New Jersey Birth Defects Monitoring Program

Trends in Birth Defect Registry-Birth Certificate Matching: The New Jersey Experience

Donald C. Finn and Leslie M. Beres-Sochka

Objective: To enhance and improve demographic-related information in a hybrid Passive/Active registry.

Methods: In order to enhance and improve the quality of data reported to the New Jersey Birth Defects Monitoring Program, the Birth Defects Registry (BDR) data files have been matched to the New Jersey birth certificate files for years 1993-2006.

Data files were matched using a deterministic scoring program created by BDR staff using SAS. Possible matches were assigned a score based upon a pre-determined protocol. Pairs scoring high enough were declared matches with no further review. Pairs with low scores were manually reviewed by program staff.

Results:

- The efficiency of the matching system has improved from 94% in 1993-1994 to 99% in 2000-2006. Since out-of-state (O-O-S) births are not issued NJ birth certificates, they were excluded from the rates if they were not reported by the birth state.
- The downward trend in O-O-S births may reflect increases in reporting of such births for which a Birth record is setup and matched by the program.
- Most of the improvement in the Adjusted Program Efficiency Rate (APE) is probably a result of improved quality of the registration review, especially the EBC check of new registrations since 2002. This is also reflected in the decrease in the number of unmatched records which were found during the manual review of low score matches.
- The very time consuming manual review, which requires multiple searches of each of the 300-400 low score registrations, seems to still be required since it secures matches on 0.5% of the registrations.

Conclusions: While time consuming and staff intensive, the process utilized in New Jersey to match the Birth Defects Registry to the New Jersey Birth Certificate files has greatly enhanced and improved the data in the Registry. The match has allowed the Registry to accurately assign each matched registrant demographic data including, but not limited to, race, ethnicity, maternal demographics, birth dates, and first and last names and to reduce the number of duplicate registrations. This matching process has provided the BDR with data on areas most likely to have errors, and has enabled staff to provide education to reporting agencies on self-improvement. Overall, it has proven to be a very useful tool for ensuring the Quality of the data in the Registry.

C1.10 New York State Congenital Malformations Registry

Development of Web-based Geocoding Applications for the Birth Defects Surveillance System in New York State

Ying Wang, Linh H. Le, Xiaohang Wang, Anna Veksler, Zhen Tao, Philip K Cross

Background: Geographic information systems (GIS) have been widely used in mapping health data and analyzing geographic distribution of disease. Mapping and spatially analyzing data normally begins with geocoding. Geocoding is the process of assigning geographic coordinates to an address so that it can be displayed and analyzed on a map. The objective of this project was to develop web-based geocoding applications for the New York State Birth Defects Surveillance system to geocode, both automatically and interactively, the birth defects cases from the Congenital Malformations Registry (CMR).

Methods: MapMarker Plus geocoding software (MapInfo, Troy, NY) equipped with a Java-based development tool (MapMarker J Server) was used to create web-based applications that send geocoding requests to a geocoding and address matching engine that resides on a UNIX server. The geocoding engine assigns coordinates to an address when it is matched to an address with coordinates in a search dictionary. The J Server accesses the geocoding engine across the Internet via New York State Department of Health (NYSDOH) Health Commerce System (HCS). The Congenital Malformations Registry (CMR) data is maintained as a relational database on a UNIX server. Both the MapMarker Address Dictionary and the ParcelPrecesion User Dictionary (the NYS real property data) were used for address matching. The Address Dictionary is a sophisticated integration of postal and street vector data. The ParcelPrecesion User Dictionary contains center points of actual parcels as well as the locations of those centroids as positioned on the street associated with each parcel.

Results: Web-based geocoding applications have been implemented for the New York State birth defects surveillance system. These applications include 1) Automated geocoding processes for selecting CMR cases, standardizing addresses, and geocoding/matching the records on a daily basis, 2) an automated records view and update program for generating reports of the newly geocoded records from the automated geocoding processes and unpdating the CMR case table with the geographic information such as coordinates (latitude and longitude) and 3) an interactive geocoding tool that goes through each unmatched record and allows users to manually edit the address for geocoding and updating CMR's case table with geocoded information.

About 98% of the CMR cases for the birth years 1995-2005 (~ 145,000 records) were geocoded at the street address level. Approximately 95% of the geocoded records used the residence-at-birth addresses and 5% used the current addresses from the CMR when the residence-at-birth addresses were not available. Geocoding result data showed that false positives in address matching were less than 0.3% of the geocoded records. Moreover, the utilization of the ParcelPrecision User Dictionary increased the address matching and geocoding accuracy.

Conclusions: The web-based geocoding applications are powerful tools that provide real-time, street level geocoding for up to 98% of birth defects cases in the CMR automatically and possibly, another 1% interactively. These automated menu-driven applications empower users to perform geocoding activities using only a PC and a web browser without installation of any GIS software.

C1.11 New York State Congenital Malformations Registry

Evaluating Hospital Discharge Data as a Source of Case Ascertainment for Population-Based Birth Defects Surveillance Programs

Ying Wang, Philip K Cross

Background: Due to the relatively high expense of collecting primary data and limited resources and authority to mandate reporting, electronically available, population-based hospital discharge data have been increasingly used for disease surveillance by public health researchers. The New York State Congenital Malformations Registry (CMR) has been using the hospital discharge files of the New York Statewide Planning and Research Cooperative System (SPARCS) as a supplementary data source since 1998 for ascertaining birth defects cases. The objectives of this study were to compare the CMR data with the hospital discharge files and identify CMR cases that were missed in the hospital discharge data files. The ultimate goal was to evaluate hospital discharge data as a source of case ascertainment for a population-based birth defects surveillance program.

Methods: CMR cases that were born to the New York State residents and were matched to birth certificate files for the years 2000-2004 were selected and matched to the SPARCS hospital discharge files for the same birth year period. A SAS program was developed to perform the match using identifying variables such as the hospital's permanent facility identifier, child's date of birth and medical record number, mother's medical record number, and the child's patient control number. The matches were conducted without using identifying variables such as patient's name and address, since the SPARCS database does not contain these variables.

Results: Out of 55,040 CMR cases selected for the study period of 2000-2004, 47,492 cases (86.3%) were matched to reports in the SPARCS hospital discharge files with ICD-9 codes that were reportable to the CMR (birth defect cases), 4,110 cases (7.5%) were matched to SPARCS reports with ICD-9 codes that were not reportable to the CMR (non-birth defect cases), and 3,438 cases (6.2%) were not matched. The percent of cases with multiple congenital malformations was significantly lower for the non-matched CMR cases (14%) and the matched CMR cases that had no reportable ICD-9 codes in the hospital discharge files (12%), compared to the matched CMR cases that had reportable ICD-9 codes in the hospital discharge files (22%). When comparing the birth defects by organ system, it was found that the percent of children with eye anomalies and birth defects in digestive and respiratory system were significantly higher for both the non-matched CMR cases matched and the matched cases that had no reportable ICD-9 codes in the hospital discharge files).

Conclusions: The study fund that about 86% of the CMR cases were matched to reports in the SPARCS hospital discharge files with ICD-9 codes that were reportable to the CMR (birth defect cases). That is, there would be 14% false positives if hospital discharge files were used to ascertain the birth defect cases. Thus, the hospital discharge files should not be used as the single source of case ascertainment for population-based birth defects surveillance programs. Birth defect diagnoses from both data sources (CMR and hospital discharge files) will be compared and medical records will be reviewed, if necessary, for the matched cases to examine the quality of the hospital discharge data.

C1.12 Texas Birth Defects Epidemiology & Surveillance

Improving Data Quality Using Random Review of Birth Defect Coding

Ann Phelps

Background and Objectives: The Texas Birth Defects Registry conducts an active surveillance program with staff performing case finding and data abstraction in almost 200 hospitals in an area of 262,000 square miles. Staff are located in 5 offices and 5 sub-offices. Caseload has increased every delivery year from about 12,000 cases added to the Registry in 1999 to almost 16,000 in 2004. Staff use a web-based application called the Intranet Abstraction System (IAS) for data entry, birth defect coding, and quality assurance activities. After entry into the IAS, selected categories of cases are sent to one of three Clinical Reviewers for electronic feedback. Additionally, all records are eligible for a Diagnosis Code Review (DCR) step which randomly selects 10% of the records for birth defect coding review by clinicians. Registry staff regularly explore methods to increase efficiency and effectiveness in all aspects of its work. The DCR process and results are worthy of closer examination to determine efficiencies that can be added to the registry data collection and processing steps.

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

Results: During a 12-month period (January 2006 through December 2006), 1,112 records went sent for DCR, 928 (85%) were marked as DCR Complete while 156 (14%) were marked as DCR Corrections. Another 13 records (1%) were determined to not be a case, and were deleted from the registry. Closer examination of the DCR Correction records revealed several interesting items. Changes were requested in 136 records of which 129 (95%) related to the birth defects listing (add, delete, change). Those birth defects changes were made 89% of the time (i.e., staff agreed with reviewer). The poster will describe the more specific examination of the DCR Correction records, including what types of corrections were requested, how frequently the corrections were actually made, what new application needs were identified, what new training needs were identified, etc.

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

C1.13 Utah Birth Defect Network

Prenatal Diagnosis and Asertainment of Orofacial Clefts in Utah 1995-2005

Miland Palmer, Marcia L. Feldkamp, and John C. Carey

Objectives: To evaluate the prenatal diagnosis and ascertainment of orofacial cleft cases in Utah from 1995 to 2005.

Methods: Orofacial cleft cases (liveborn, stillborn, and terminations) collected by the Utah Birth Defect Network (UBDN) from 1995 to 2005 were analyzed with regard to prenatal diagnosis and reporting sources. Cases were separated into three groups by type of defect, cleft lip with cleft palate, cleft lip alone, cleft palate alone. For the purpose of this project cleft cases identified as not otherwise specified were excluded (n=6). Each group was also stratified by prenatal diagnosis. The most common sources of ascertainment for overall clefts were identified. Age at time of first report received by the UBDN was calculated by subtracting the date the UBDN received the first report from the child's date of birth (or date of delivery for stillbirths and terminations). The mean age at time of first report was calculated for each sub-group. The most common location for first abnormal ultrasound was evaluated for all prenatally diagnosed cases. The rate of prenatal diagnosis and the age at time of first report was compared across all years.

Results: From 1995 to 2005 there were 929 cases of orofacial clefts identified. Overall 324 (34.9%) cleft cases were prenatally diagnosed. Prenatally diagnosed cases included 228 (70.4%) cleft lip with cleft palate, 94 (29.0%) cleft lip alone, and 2 (0.62%) cleft palate alone. Of those prenatally diagnosed 136 (42.0%) were diagnosed in a community physician's office (e.g. obstetrician), 126 (38.9%) were diagnosed in a prenatal diagnostic center (e.g. perinatologist), 59 (18.2%) were diagnosed at a community hospital (e.g. radiologist), and for 3 (0.93%) the location was unknown. The prenatal diagnostic center was the only reporting source that was unique to prenatally diagnosed cases. The average age at time of first report was 71.2 days for all cases combined, 91.4 days for cases not prenatally diagnosed and 34.5 days for prenatally diagnosed cases. The average age at time of first report has decreased over time from 121.1 days in 1995 to 27.3 days in 2005.

Conclusions: The UBDN has observed a slight increase in the prenatal diagnosis of orofacial clefts in Utah over the 11 year time period. The increase may be due to increasing technology, improved UBDN methodology, or some other outside factor. As the UBDN has matured, increasing the number of reporting sources and improving processes, a considerable decrease in the average age at time of first report has been realized. The UBDN should continue to improve relationships and processes with reporting sources to further increase timeliness of reporting as improving technology is increasing the number of defects being prenatally diagnosed.

C1.14 Vermont Birth Information Network

Passive Case Ascertainment: An Evaluation of Data Sources

Peggy Brozicevic, John Burley and Leah Burke

Objective: In 2006, the Vermont Birth Information Network began collecting information about Vermont-resident children diagnosed in the first year of life with one or more of 32 structural and chromosomal birth defects. The program uses passive case ascertainment that relies on four main data sources: vital records, Medicaid claims, reports from hospitals and physicians, and records maintained by the Vermont Department of Health's Children with Special Health Needs program. Every case is reviewed by a clinical geneticist who determines if the diagnostic criteria in the child's medical record are consistent with the case definition for one or more of the conditions tracked by the program. The goal of this study is to evaluate the data sources in terms of the likelihood that a case will be reported and the accuracy of the prospective diagnosis.

Methods: Thus far, approximately 60% of the clinical charts of infants born in 2006 who were reported to have a birth defect of interest to the program were reviewed by a clinical geneticist. Each prospective case was coded as "confirmed" or "ruled-out." The number of confirmed cases, and the percentage of confirmed cases that were identified by each data source, were tabulated by condition. Similarly, the number of cases reported by each data source, and the percentage of cases that were subsequently confirmed, were tabulated by condition. Where not all conditions were reportable in a particular data source – for example in the case of birth certificate records – non-reportable conditions were excluded from the denominator in the calculation of the percentage of confirmed cases reported. For sources, such as Medicaid claims and death certificates, where not all cases were included in the population covered by the data set, the denominator used to calculate of the percentage of confirmed cases was adjusted accordingly.

Results: Confirmed cases of the selected birth defects were least likely to be reported on the birth certificate, with only 6% of possible cases being reported. The most comprehensive data source was hospitals and physician reports, with 96% of confirmed cases included in this source. On the other hand, only 54% of all cases reported by hospitals and physicians were confirmed during the clinical review process, compared with 86% of birth certificate records that were confirmed. Some conditions reported by hospitals and physicians, and by Medicaid, were much less likely to be confirmed during clinical chart review. For example, only 13 out of 60 (22%) cases of atrial septal defect, and 2 out of 30 (7%) cases of patent ductus arteriosus reported by hospitals and physicians were confirmed, whereas 34 of 38 (89%) of ventricular septal defects were confirmed during chart review.

Conclusions: Data sources used in a passive case ascertainment system were found to vary widely in terms of their accuracy and completeness. Within a single data source, specific conditions were more likely than others to be over-reported or to be under-reported.

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

C2.1 Department of Defense Birth and Infant Health Registry

Hemangiomas and Associated Birth Defects Among Infants Born to U.S. Military Families

Anna T Bukowinski, Margaret A K Ryan, Donald J Slymen, Carter J Sevick, and Tyler C Smith

Background: Hemangiomas, benign vascular tumors, are estimated to occur in 4-10% of infants. Some infants with hemangiomas also have birth defects, but the relationships between these diagnoses are not well defined.

Methods: The U.S. Department of Defense Birth and Infant Health Registry identified all diagnoses of hemangiomas and birth defects in singleton infants born to US military families between 1998 and 2003. Cluster analysis and multivariable logistic regression were applied to quantify relationships between diagnoses.

Results: Among 467,295 infants, 5,313 were diagnosed with hemangiomas. These infants were more likely to be female, of white/non-Hispanic race/ethnicity, and born to older mothers. In multivariable models, infants with hemangiomas were also more likely to be diagnosed with spina bifida, hydrocephalus, or anomalies of the female genitalia.

Conclusions: These findings have implications for better understanding the etiology of congenital conditions occurring concomitantly. Analyses also highlight the value of DoD work in addressing public health issues of concern.

C2.2 Department of Defense Birth and Infant Health Registry

Does Smallpox Vaccine Impact the Reproductive Health of Service Members? Evaluations of Infertility, Adverse Pregnancy Outcomes, and Birth Defects

Gumbs GR, Conlin AMS, Jacobson IG, Sevick CJ, Snell KJ, Smith TC, and Ryan MAK

Background: The compulsory smallpox vaccination policy, initiated in early 2003, introduced a unique occupational exposure given to a large population of reproductive-aged US military service members. The short-term adverse effects of the vaccine are fairly well known. However, aside from rare cases of fetal vaccinia, potential effects of smallpox vaccination on reproductive health are less well understood. Many efforts, including the National Smallpox Vaccine in Pregnancy Registry, have been established to address potential reproductive health concerns.

Methods: Passive and active surveillance methods are used to obtain exposure and health outcome data. Infertility, pregnancy losses, preterm births, and birth defects are among the diagnoses captured and validated. These outcomes are linked to demographic, vaccination, and exposure data, and evaluated with multivariable models.

Results: Among women vaccinated against smallpox during pregnancy, there have been no increases in pregnancy losses, no increases in birth defects, and no cases of fetal vaccinia, to date. Analyses of infertility, maternal exposure before pregnancy, and paternal exposure before conception, are ongoing.

Conclusions: These represent the first studies to address the important and complex issues of reproductive health after smallpox vaccination. Results of preliminary research have been reassuring.

C2.3 Georgia Birth Defects Reporting and Information System

Neighborhood and Individual Characteristics as Predictors for Birth Defects in Metropolitan Atlanta, Georgia, 1994-2005

Jennifer C. Smith and Debra L. Thompson

Background: Most research conducted in the area of adverse birth outcomes has focused on the social, behavioral, cultural and environmental factors. The outcome variables for these studies have consistently been low birth weight, preterm delivery and infant mortality. While we know from previous research that social, behavioral, cultural and environmental factors are related to low birth weight, preterm delivery and infant mortality, it is not clear if these same factors are associated with certain birth defects – particularly, the more severe defects – including those of the central nervous and cardiovascular systems, and orofacial, muskuloskeletal, and chromosomal defects. This study aims to determine any associations between neighborhood level variables, and birth defects, specifically congenital anomalies, after controlling for individual risk factors. The following three questions are addressed through this research study: Do individual (social, cultural, and behavioral) level factors increase the risk of birth defects? Do neighborhood and environmental level factors increase the risk of birth defects? Is there an association between individual and neighborhood level factors and congenital anomalies?

Methods: This study analyzes the birth records of 563,042 babies born to mothers residing in metropolitan Atlanta, Georgia, at the time of birth defect diagnosis, between the years 1994 and 2005. All parental risk factor data was collected from birth, vital, and death records of Clayton, Cobb, Dekalb, Fulton and Gwinnett Counties, Georgia, from 1994-2005. The 1990 and 2000 U.S. Census was used to draw neighborhood level data, including socioeconomic, sociodemographic, and behavioral characteristics. We utilized multilevel analyses, including logistic regression and Hierarchical Generalized Nonlinear Modeling, to investigate associations between neighborhhod level variables, individual level variables and birth defects. SAS statistical software was used to analyze relationships among variables.

Results: Of the 563,042 babies included in the study, 73 (0.01%) and 109 (0.02%) were born with spina bifida and anencephalus, respectively. Down Syndrome was diagnosed in 150 (0.03%) of babies. Circulatory or respiratory anomalies (0.09%) and heart malformations (0.08%) accounted for the largest percentage of congenital anomalies. Twelve percent of babies were born at <37 weeks gestation, and 9% weighed <2500g. Sixteen percent of mothers had experienced a previous fetal death. Five percent of mothers drank alcohol or smoked tobacco during pregnancy. Multilevel and neighborhood level analysis results are pending.

Conclusion: By considering neighborhood characteristics, in addition to individual risk factors, researchers can better understand the etiology of congenital anomalies, the most severe of birth defects. In doing so, prevention and intervention programs targeting populations as high(er) risk for birth defects might be better tailored for their audiences and, therefore, more successful at decreasing the number of birth defects. This particular study's outcomes will be beneficial for those conducting research and prevention efforts in maternal and child health, and assist in the identification of at-risk communities, as well as provide further evidential support for birth defect prevention programs and policy.

C2.4 National Birth Defects Prevention Study

Maternal Thyroid Disease and Cardiovascular Malformations

M Browne, A Caton, S Rasmussen, C Druschel, A Lin, M Canfield, P Romitti

Background: Thyroid disorders are common among women of reproductive age. Thyroid function plays an important role in cellular oxidative stress. It has also been hypothesized that high triiodothyronine activity stimulates the heart, causing irregular heart beat which may alter hemodynamic flow, and cause congenital anomalies. The results of previous epidemiologic studies of thyroid disease or thyroid medication use and cardiovascular malformations (CVMs) have been inconsistent. The detailed case classification protocol and large number of cases in the National Birth Defects Prevention Study (NBDPS) allow analysis of specific heart malformation subgroups.

Methods: We examined the association between maternal thyroid disease and CVMs in the NBDPS. Cases with simple, isolated CVMs were considered separately from those with multiple CVMs or additional non-cardiac malformations. The NBDPS interview asks about all medications used from the periconceptional period through the end of pregnancy but does not include a specific question about thyroid disease. Maternal thyroid disease status was based on thyroid medication use or thyroid disease reported in response to an open-ended question about other diseases. Responses to the open-ended question were coded (thyroid disease/not thyroid disease) by a clinician blinded to case status. Cases and controls with maternal history of pregestational diabetes were excluded from the analysis. Logistic regression models were used to estimate adjusted odds ratios and 95% confidence intervals for the association between maternal thyroid disease/medication use and CVMs, while controlling for confounding variables. Covariates evaluated as potential confounders included maternal age, race/ethnicity, education, prepregnancy body mass index, gestational diabetes, smoking, alcohol use, and state of residence at the time of delivery.

Results: In preliminary analysis of 4974 unaffected controls and 5410 cases, 1.7% of control mothers and 2.2% of case mothers reported thyroid disease or thyroid medication use. Thyroid hormone use was reported most frequently; < 8% of thyroid medication users reported an antithyroid medication. The adjusted odds ratios for the association between maternal thyroid disease and CVMs were elevated for many of the specific CVM subtypes examined, however; most estimates were less than 2.0 and none were statistically significant.

Conclusions: We did not find a significant association between maternal thyroid disease and specific CVMs; however, our findings cannot rule out small to moderate increases in risk. Exposure was too infrequent to examine hyperthyroidism/antithyroid medication use separately; these exposures merit further study.

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

Herbal Use Before and During Pregnancy

Cheryl S. Broussard, Carol Louik, Margaret A. Honein, Allen Mitchell, and the National Birth Defects Prevention Study

Objective: Though safety concerns have been identified for some herbal products, many continue to be widely used. In contrast to prescription and over-the-counter medications, there is no requirement to demonstrate safety or efficacy prior to marketing, and the safety of herbal products during pregnancy is unestablished. Because the extent of herbal use in pregnant women is unclear, this analysis was conducted to estimate the prevalence and patterns of herbal use among women immediately before and during pregnancy.

Methods: The National Birth Defects Prevention Study (NBDPS) is an ongoing multisite case-control study that aims to identify environmental and genetic risk factors for major birth defects. The NBDPS provides an opportunity to describe herbal use in a population-based sample of women who had infants without major birth defects (control mothers) in varied geographic settings across the United States. Women were interviewed by telephone to ascertain exposures immediately before and during pregnancy. Specific questions about herbal use (defined as any product containing a plant, plant part, or plant extract, excluding topicals) were initiated in mid-2000, and this descriptive analysis included data for women with estimated dates of delivery from 1998 through the end of 2003.

Results: Of 3,325 control mothers, 299 (9%) reported use of any herbal product in the 3 months before pregnancy or anytime during pregnancy. There was considerable geographic variation in the prevalence of use, ranging from 3% (North Carolina) to 16% (Utah). Women over age 30 had a higher prevalence of use than younger women, as did women with more than a high school education. Lower income (<$20K) was associated with a lower prevalence of use. Prevalence did not vary by race or ethnicity. The most commonly reported single-component herbal product was echinacea (1%). Among all single- and multiple-ingredient products reported, the most common components were ginger and chamomile (1.4% each), ephedra (1.3%), echinacea and herbal tea (1.0% each), and ginseng (0.8%). Among women who took herbals, use was slightly more common in the 3 months before pregnancy (38%) than in the first (29%), second (33%), or third (32%) trimesters. Reported reasons for use were often non-specific, with the most common being "remedies", "vitamins", respiratory conditions, morning sickness, and urinary tract infections. A considerable proportion of the multiple-component products had labeled indications that included weight loss or body enhancement.

Conclusions: Use of herbal products in the periconceptional and prenatal periods was relatively common among study women. Much of the reported exposure was through use of multiple-component products, many of which contained ephedra (which is known to be associated with adverse health effects). The possibility of unrecognized maternal or fetal effects of other herbal components deserves continued attention, and pregnant women and those contemplating pregnancy should discuss potential risks and benefits of herbal use with a health care provider.

Disclaimer: The findings and conclusions in this presentation are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention.

C2.6 National Center on Birth Defects and Developmental Disabilities, CDC

Maternal Caffeine Intake during Pregnancy and Risk of Orofacial Clefts

SA Collier, ML Browne, MA Honein, SA Rasmussen, and the National Birth Defects Prevention Study

Background: Exposure to moderate levels of caffeine during pregnancy is relatively common, but little is known about the potential association between higher levels of caffeine intake and major birth defects including orofacial clefts. In addition, caffeine might interact with other exposures, such as maternal smoking, to increase risk.

Methods: The National Birth Defects Prevention Study is a population-based case-control study of major birth defects that collects information on maternal characteristics and exposures through a telephone interview. The study excludes infants with single-gene disorders and chromosomal abnormalities. Mothers are asked to report caffeine intake from coffee, tea, and sodas in the year before pregnancy. We assessed the association between level of caffeine intake (<10, 10-99, 100-199, 200-299, and ≥300 mg/day), frequency of consuming each major source of caffeine (coffee, tea, soda), and cleft lip with/without cleft palate (CL/P) or cleft palate only (CPO). Models were adjusted for smoking, maternal age, and family history of a cleft. We also stratified by infants with an isolated cleft and those with multiple major unrelated defects. We included infants born October 1997--December 2003. Infants whose cleft was secondary to holoprosencephaly or amniotic band sequence were excluded from this analysis.

Results: Interviews were completed by mothers of 1,316 infants with CL/P, 707 infants with CPO, and 4,839 control infants. Among mothers of control infants, 11.9% reported consuming ≥300 mg caffeine per day and 15.5% reported consuming <10 mg caffeine per day; high level consumption (≥3 cups per day) was reported for coffee by 8.0%, for tea by 4.2%, and for soda by 15.3%. While some effect estimates were elevated for moderate levels of caffeine intake (100-199 mg/day), estimates were closer to the null for high levels of caffeine and no associations were statistically significant. Mostly null associations were observed for consumption of < 3 cups per day of coffee, tea, or soda when assessed individually. For high level coffee consumption, the only statistically significant result was a protective effect for CPO with multiple defects (OR=0.37, 95% CI 0.15-0.95). High level tea consumption was associated with isolated CL/P (OR=1.36, 95% CI 1.01-1.82) and CPO with multiple defects (OR=3.19, 95%CI 1.79-5.70). High level soda consumption was associated with CPO with multiple defects (OR=1.67, 95% CI 1.01-2.76).

Conclusion: Our data do not suggest an overall association between maternal caffeine intake and CL/P or CPO. However, some associations with high level intake of specific sources of caffeine warrant additional investigation.

Disclaimer: The findings and conclusions in this presentation are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention.

C2.7 National Center on Birth Defects and Developmental Disabilities, CDC

Maternal Prepregnancy Body Mass Index and Congenital Heart Defects: Results from the National Birth Defects Prevention Study, 1997-2003

A Correa, SM Gilboa, LM Besser, LD Botto, SA Rasmussen, DK Waller, M Cleves, CA Hobbs, T Riehle-Colarusso, and the National Birth Defects Prevention Study

Background: Prepregnancy obesity is associated with adverse pregnancy outcomes, including several phenotypes of birth defects. Increased risk of congenital heart defects (CHD) as a whole has been documented in relation to maternal obesity, yet few previous studies have investigated specific CHD phenotypes. Studies that have examined specific phenotypes report inconsistent results. Data from the National Birth Defects Prevention Study (NBDPS) were used to explore the relation between obesity (body mass index [BMI]: >30.0 kg/m^2), overweight (BMI: 25.0-29.9 kg/m^2), and underweight (BMI: <18.5 kg/m^2) status and the occurrence of CHD.

Methods: Mothers enrolled in the NBDPS, with infants born on or after 1 October 1997 with an estimated date of delivery on or before 31 December 2003 were eligible for the study. Mothers reporting pregestational diabetes (n=185 cases; n=26 controls) and those with missing information for BMI (n=230 cases; n=208 controls) were excluded from the analysis. Cases with complex heart defect (n=358) were also excluded. The final analysis included 4885 cases with CHD and 4774 controls. The analysis focused on isolated, simple cases, selected isolated associations, and multiple cases. Potential confounders included in multivariable logistic regression models were maternal age, race/ethnicity, education, parity, smoking during the period of the month before pregnancy or the first month of pregnancy (B1-P1), alcohol use during B1-P1, folic acid supplement use during B1-P1, hyptertension during pregnancy, and household income. Study center was adjusted for using conditional logistic regression. Analyses were limited to CHD phenotypes with at least 50 isolated cases. Potential effect measure modification by gestational diabetes, race/ethnicity, and folic acid supplement intake were investigated.

Results: Among mothers of control infants, 6% were underweight, 22% were overweight, and 15% were obese. The odds of having a baby born with any simple, isolated heart defect were increased for overweight (OR=1.20; 95% CI=1.07-1.35) and obese (OR=1.22; 95% CI=1.07-1.40) mothers compared with mothers of average BMI (18.5-24.9 kg/m^2). These associations were stronger among cases with multiple defects ([OR=1.34; 95% CI=1.08-1.65] and [OR=1.51; 95% CI=1.20-1.90] for overweight status and obesity respectively). Overweight status and obesity were also risk factors for simple isolated cases of pulmonary valve stenosis (OR=1.41; 95% CI=1.08-1.83; OR=1.46; 95% CI=1.09-1.95) and the grouping of right ventricular outflow tract obstruction defects (OR=1.34; 95% CI=1.07-1.69; OR=1.35; 95%CI=1.05-1.75). Several other CHD phenotypes were associated with either overweight status or obesity. For some CHD phenotypes, obesity was a stronger risk factor among women diagnosed with gestational diabetes in the index pregnancy (5.5% of cases; 3.5% of controls). There was also evidence of effect measure modification by race/ethnicity; overweight and obese Hispanic women appear at increased risk of selected phenotypes. Underweight status was not associated with CHD.

Conclusions: Maternal overweight status and obesity appear to be associated with the occurrence of selected CHD. However, exposure misclassification due to self-reported height and weight data is possible and differential patterns of missing data may be sources of bias. Preconception care should address the importance of optimal prepregnancy health which includes achieving a healthy body mass index.

C2.8 New York State Congenital Malformations Registry

Air Pollutants and Birth Defects in New York State

Erin Bell, Lei Chen, Alissa Caton, Charlotte Druschel, and Shao Lin

Background: In 2002, the New York State Department of Health was one of 24 state and local health departments funded by the Centers for Disease Controls and Prevention's (CDC) Environmental Public Health Tracking Program (EPHT). New York State's EPHT system was designed to assess potential adverse health outcomes associated with ambient air pollutants (O_3 and PM_{10}). New York State is also one of 10 study sites for the CDC funded National Birth Defects Prevention Study (NBDPS). This is a multi-site population based case-control study of non-chromosomal birth defects. The NBDPS collects extensive information on occupational and environmental exposures during pregnancy as well as maternal medical histories via a computer assisted telephone interview.

Animal studies suggest that air pollutants may be associated with adverse reproductive effects. In previous studies, conotruncal and septal malformation risk was increased among women residing in areas with high ozone and PM10 exposure, respectively.

Methods: We examined ambient air pollutant exposure during the critical period and selected birth defects both statewide and among participants in the NBDPS. Birth certificate data obtained from the Vital Statistics Registry were used to identify all singleton births occurring between 1995-2001 to mothers living (as determined by the address reported on the birth certificate) within the NYSDEC defined O_3 buffers and 1995-1998 for mothers living within the PM_{10} buffer regions. We linked the births to the New York State Congenital Malformations Registry (CMR) to identify the major birth defects that occurred during the study period. Approximately 40,000 infants with birth defects were reported to the registry between 1995-2001 with genitourinary, musculoskeletal and heart defects the most commonly reported outcomes. We examined each birth defect subtype separately for each air pollutant using ordinary logistic regression. Data on potential confounders were obtained from the birth certificate data and adjusted for as appropriate in our final models. From the study cohort described above, we identified infants that are also enrolled in the NBDPS and assigned their exposure to ozone and PM_{10} during the critical period as appropriate. For this case-control analysis, data on potential confounders were obtained from the questionnaire data.

Results/Conclusions: Overall, no significant associations were observed for exposure to ozone and PM10 during the critical period and selected birth defects in either cohort or case-control analyses. Limited power prevented the examination of many case subtypes. Meteorologic factors, other ambient air pollutants, and indoor air pollutants were not considered.

C2.9 New York State Congenital Malformations Registry

Congenital Malformations, Low Birth Weight, and Small for Gestational Age in a Community Affected by Soil Vapor Intrusion

Alissa Caton, Steve Forand, Elizabeth Lewis-Michl, Karen Nolan

Background: Soil vapor intrusion resulted in indoor air exposures to tricloroethene (TCE), perchloroethene (PCE), and other volatile organic compounds (VOCs) in an area with approximately 3,000 residents in Endicott, New York. In response to community concerns, the birth prevalence of congenital malformations, low birth weight, small for gestational age, and preterm births was evaluated among residents in comparison with births in New York State (NYS) excluding New York City.

Methods: Using NYS Congenital Malformations Registry and Vital Records data, prevalence ratios (PR) from Poisson regression for congenital malformations (1983-2000), odds ratios (OR) from logistic regression for low birth weight and small for gestational age (1978-2003), and 95% confidence intervals were calculated, adjusting for maternal age, race/ethnicity, education, infant sex, birth-year, adequacy of prenatal care, and parity. For the latest birth years, adjustment for smoking status was performed.

Results: Prevalence ratios for total cardiovascular malformations (PR=1.94, CI:1.21-3.12), major cardiovascular malformations (PR=2.52, CI:1.20-5.29), and conotruncal defects (PR=4.83, CI:1.81-12.89) were elevated. Low birth weight (OR=1.26, CI:1.00-1.59), term low birth weight (OR=1.41, CI:1.01-1.95) and small for gestational age (OR=1.22, CI:1.02-1.45) births were elevated. Analyses using available smoking data indicated smoking played a role in the low birth weight results. Incomplete control of socio-economic factors may have played a role in the cardiovascular malformation and low birth weight findings.

Conclusions: Analytic epidemiologic research, including additional areas with similar VOC exposures in order to increase study size, is needed to follow up on these suggestive findings.

C2.10 New York State Department of Health

Maternal Asthma, Asthma Medication Use and the Risk of Congenital Heart Defects

Shao Lin, Michele Herdt-Losavio, Lenore Gensburg, Elizabeth Marshall, Charlotte Druschel

Objective: Asthma is a common problem complicating pregnancy. Several drugs are considered acceptable for use during pregnancy, although none have been classified as safe. Few studies have assessed the impact of maternal asthma/medication use on the fetus. The purpose of this study was to determine if cardiac congenital malformations in offspring were associated with maternal asthma and/or asthma medication use.

Methods: A population-based case-control study was conducted in New York State (NYS) to determine if cardiac congenital malformations in offspring were associated with maternal use of asthma medication and whether these cardiac malformations were associated with maternal asthma. Cases were cardiac anomalies in the NYS Congenital Malformations Registry diagnosed from 1988-1991. Controls were live births without any major birth defects randomly selected from birth certificates and frequency matched by year of birth. Data was collected through a 30 minute telephone interview. Exposure was divided into four groups: maternal asthma with medication use, maternal asthma without medication use, medication use without asthma, and no asthma/ no medication use. Asthma medication use included bronchodilators and/or anti-inflammatories. We also examined medication use by stage of pregnancy that the woman began using medication and simultaneous use of multiple medications. The group of non-asthmatics not using asthma medication was used as the comparison group for all exposure indicators. Unconditional logistic regression analysis was used to calculate odds ratios to estimate the risk of congenital heart defects for the various exposure groups. Final models were adjusted for sex of child, maternal history of chronic diabetes, family history of child with congenital heart defect, maternal caffeine use, maternal fever, prenatal vitamin use, and trihalomethane exposure.

Results: A total of 502 (59.4%) cases and 1066 (53.8%) controls participated. A positive association was seen between any heart defect and asthmatic patients using medication (odds ratio (OR)=2.4, 95% Confidence Interval (95%CI) (1.23, 4.68)), specifically when starting medication during the critical period (1 month prior to conception through the date pregnancy is known). Elevated, but not significant, associations were observed between heart defects and asthmatics not using medication. No association was observed between heart defects and non-asthmatics using asthma medications. When considering types of medication used, offspring of asthmatics using bronchodilators had an increased risk of any heart defect (OR=2.09; 95%CI (1.03, 4.23)). Frequent use of bronchodilators may suggest poorly controlled asthma. No elevated odds ratios were observed among those who used anti-inflammatories only. A clear trend was found for the number of medications used, with multiple medication use (suggesting severe asthma) having the strongest association (OR=3.1; 95% CI: 1.0, 9.5). Again, a clear trend emerges for duration categories with use throughout the entire pregnancy showing the strongest association compared to short duration of use.

Conclusions: These results suggest that both maternal asthma status (controlled versus uncontrolled; severe versus mild) and asthma medication use, particularly bronchodilators, may play a role in cardiac malformations in their offspring. Further studies should examine maternal asthma status more carefully and separate these effects from maternal asthma medication use effects on cardiac defects.

C2.11 Oklahoma Birth Defects Registry

Exploring the Dataset on Selective Serotonin Reuptake Inhibitors (SSRIs) Drugs among Mothers of Infants in the Oklahoma Birth Defects Registry, 1994-2005

Elizabeth Kruger and Kay Pearson

Background: Numerous randomized clinical studies have shown the efficacy of Selective Serotonin Reuptake Inhibitors (SSRI) drugs in the acute treatment of depression. If untreated, relapses of depressive symptoms occurred. Several studies pointed out that the SSRIs are effective in treating depressive symptoms in pregnant mothers; however, many demonstrated that infants who were born to mothers who took SSRI antidepressant drugs early during their pregnancy were more likely to have heart defects.

Methods: The Oklahoma Birth Defects Registry (OBDR) collects information on prescription drugs taken by mothers during pregnancy. Data collected on mothers prescribed with the SSRIs and their infants from 1994 through 2005 were analyzed. The SSRI drugs in the OBDR study included Prozac, Zoloft, Paxil, Celexa, Fluoxetine, Sarafem Pulvules, Luvox and Citalopram. We conducted demographic descriptive analyses; rates were calculated if fields for denominator birth data were available. Major types of birth defects and chromosomal abnormalities were identified. Chi-squared statistics were used to determine statistical differences between specific heart defects among SSRI infants for several variables of interest. Geocoded cases were mapped using the GIS software.

Results: A total of 729 (3.1%) OBDR mothers were prescribed SSRI antidepressant drugs during pregnancy. Of these, 41% took Zoloft, 27% took Prozac, 21% took Paxil, 8% took Celexa and 3% reported Fluoxetine, Sarafem, Luvox and Citalopram. The annual SSRI rates were 12.4 per 10,000 pregnant women. The rates increased with age, with the highest rates (30.5 per 10,000) among mothers between 40 and 45 years of age. The SSRI mothers were more likely to be unmarried and college educated. Caucasians and American Indian/Alaskan Native had much higher SSRI rates than Black or Hispanic mothers. Infants born to SSRI mothers had lower birth weight and lower gestational age at birth. Congenital heart defects are the largest category of defects identified. Heart defects accounted for nearly 31% of all defects in the SSRI sample, followed by 23% musculoskeletal defects.

Conclusions: Only 3% of the women in the 1994-2005 OBDR database reported taking the SSRI drugs during pregnancy. Heart Defects accounted for nearly one-third of the major defects noted among the infants in the sample. Limitations of the data include lack of timing of gestational age with drug use. The medication could have been taken after organogenesis occurred. In addition, dose of medication was not available. The efficacy of SSRI drugs in the acute treatment of depressive symptoms among pregnant women requires more research to determine predictive risks for birth defects.

C2.12 Rhode Island Birth Defects Program

Examining the Association between Maternal Risks and Birth Defects in Rhode Island, 2002-2006

William Arias and Samara Viner-Brown

Objectives: The RI Birth Defects Program is linked to a population-based integrated child health information system, KIDSNET, which includes information from ten child health programs, including the Newborn Developmental Risk Screening (NDRS) Program. Every baby born in RI is screened for developmental factors (medical, demographic and psychosocial) through the NDRS. Families with babies determined to be "at-risk" are offered home visits and program referrals. The purpose of this study was to examine the level of risk of birth defects cases associated with maternal factors reported in the NDRS by comparing mothers of newborns with a birth defect and mothers of newborns without a birth defect, and to identify subgroups at higher risk to monitor follow-up care and appropriate services.

Methods: The study population consisted of women who gave birth in and were residents of RI during 2002-2006. A case-control design was selected to examine the cases (women who gave birth to a newborn with at least one birth defect) and the comparison group (women who gave birth to a newborn without a birth defect) against selected maternal risk measures from the NDRS database [history of substance abuse, intervention by the RI Department of Children, Youth and Families (DCYF), history of mental health illness, and diagnosis of a disability]. These groups were also stratified by maternal characteristics (mother's age group, residence, education level, type of insurance, and marital status). Odds ratio estimates were used to measure the outcome of risk variable and maternal characteristic measures. Confidence intervals (95%) of odds ratio estimates and p-values determined the significance of the analysis.

Results: There were 3,274 birth defects cases and 58,034 controls in the comparison group. Mothers of newborns with a birth defect were significantly associated with a history of substance abuse and DCYF intervention, with an odds ratio of 1.47 (CI 1.22-1.76) and 1.45 (CI 1.16-1.81), respectively. Maternal history of mental health illness and diagnosis of a disability did not show a significant association with birth defects. History of substance abuse and DCYF intervention showed significant association with birth defects among almost all strata, particularly women over the age of 35 (OR 3.17 and 4.28), women with no insurance at the time of delivery (OR 4.95 and 4.21), and single women (OR 3.12 and 2.94). Compared to mothers of newborns without a birth defect, single mothers of newborns with a birth defect were more likely to have a history of substance abuse (OR 3.12 CI 2.54-3.84) and DCYF intervention (OR 2.94 CI 2.30-3.76), but married mothers of newborns with a birth defect were not.

Conclusions: Women who have a history of substance abuse and involvement with DCYF are at higher risk for having a newborn with a birth defect, especially single women, than women who do not have these characteristics. Early identification of and appropriate services to high-risk women may help reduce poor birth outcomes in RI.

C2.13 Texas Birth Defects Epidemiology and Surveillance Branch/Texas Center BDRP

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

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

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

Methods: We analyzed data from Hispanic and non-Hispanic white mothers who completed the interview and had expected delivery dates from October 1997 through 2003. Our dataset consisted of 249 parents of cases of anencephaly, 552 cases of spina bifida, and 5,008 non-malformed controls. Hispanics were stratified by country of birth for each or both parent(s) (U.S., Mexico/Central America); length of time in the U.S. (<5 vs. 5+ years); and predominant language (English vs. Spanish). Crude and adjusted odds ratios and 95% confidence intervals were calculated, using whites as the referent group.

Results: For U.S.-born Hispanic parents, crude odds ratios (cORs) for spina bifida were modestly but not significantly elevated, relative to whites (cOR range=1.2 to 1.3). Odds ratios for Hispanic parents born in Mexico or Central America were much higher (cOR range=2.2 to 3.0). If both mother and father were born in Mexico/Central America and they had both lived in the U.S. <5 years, the cOR was 3.3 (95% CI=1.5-7.4), compared to white parents. Similar results were observed for predominant language. For Hispanics who primarily spoke or interviewed in English, cORs for spina bifida were modestly elevated, relative to whites (cOR range=1.2 to 1.4). Odds ratios were considerably higher for Hispanic mothers who interviewed in Spanish, or for mothers and fathers for whom the predominant language at home was Spanish (cOR range=1.8 to 2.2). For anencephaly, the risk for both U.S.-born Hispanic mothers and English speaking parents was roughly twice that of white mothers. For example, if both the mother and father were U.S.-born Hispanic (vs. both being white), the cOR for anencephaly was 2.3 (95% CI=1.4-3.9). If fathers were born in Mexico/Central America, cORs for fathers or both parents were considerably higher (range=2.5-2.8). Results were similar if adjusted for other factors.

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

C2.14 Texas Birth Defects and Epidemiology Branch/Texas Center BDRP

Birth Defects in Hispanics: Are they related to Mothers' Birthplace?

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

Objectives: Studies comparing the risk of birth defects among foreign-born Hispanic mothers with their US-born counterparts have reported inconsistent findings. The National Birth Defects Prevention Study (NBDPS), a multi-center population-based case-control study, provides a unique opportunity to examine the relationship between Hispanic mother's nativity and birth defects in a large US population. This study examines the association between birth defects and maternal birthplace among Hispanics, and analyzes the relationship between duration of stay for foreign-born Hispanics and birth defects.

Methods: The NBDPS collects data on almost 30 different birth defects, country of birth and parental socio-demographic characteristics. We examined responses of questions on birthplace for only Hispanic mothers, and calculated percent distributions of selected maternal characteristics. Using logistic regression, we also calculated odds ratios and their 95% confidence intervals, to assess the relationship between mother's birthplace outside the US and 17 selected birth defects, using US-born Hispanic mothers as referent group. We stratified foreign-born Hispanic women into those who lived in the US for ≤5 years and those who lived in the US for >5 years, and examined the association between foreign-born Hispanic mother's duration of stay in the US and birth defects. All analyses were adjusted for mother's age at conception, body mass index, years of education attained and study site.

Results: In total there were 3148 cases and 1123 control Hispanic mothers. For foreign-born control Hispanic mothers, the country of birth reported most often was Mexico (77%), followed by El Salvador and Dominican Republic (4% each). Overall, Hispanic mothers born in the US were almost 2 times more likely to be obese compared with their foreign-born counterparts. Compared with US-born Hispanic mothers, Hispanic women who were born outside the US and lived in the US for less than or equal to 5 years were 67% less likely to deliver babies with craniosynostosis compared with US-born Hispanic women. Foreign-born Hispanic mothers who lived in the US for >5 years were more likely to deliver babies with longitudinal limb defects [OR=2.13 (1.06, 4.31)] than those born in the US. Similar results were observed when we examined cases of isolated birth defects.

Conclusions: Our findings that foreign-born Hispanic mothers had less risk of delivering babies with craniosynostosis are consistent with previous reports. The differences in the occurrence of birth defects among different Hispanic nativity groups and duration of stay in the US might be due to differences in ascertainment or differences in cultural norms and behavioral characteristics.

C2.15 Texas Birth Defects Epidemiology and Surveillance Branch/Texas Center BDRP

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

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

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

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

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

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

C2.16 University of South Florida Birth Defects Surveillance Program

Are Hispanics at Increased Risk of Gastroschisis?

Marie G. Pierre, Jennifer L. Kornosky, Jason L. Salemi, Kimberlea W. Hauser, and Jane D. Carver

Background: Recent studies have reported that the prevalence of gastroschisis, an abdominal wall defect, is increasing; however, with a largely unexplained etiology, the cause of this rise is unknown. Some reports suggest that Hispanics are at higher risk of gastroschisis. Florida's diverse population and large number of Hispanic births afford the opportunity to explore risks of gastroschisis within Hispanic subgroups.

Methods: Data for this study were obtained from the Florida Birth Defects Registry (FBDR), a population-based passive surveillance system. Infants are eligible for inclusion in the FBDR if they are live-born to a Florida resident and have at least one birth defect diagnosed within the first year of life. Infants born between January 1, 1998 and December 31, 2003, inclusive, were eligible for this analysis. Gastroschisis cases were first identified from the FBDR as those infants with the 756.79 ICD-9-CM code ("other congenital anomalies of the abdominal wall") and then differentiated from infants with other abdominal wall defects (i.e. omphalocele) using the 54.71 ICD-9-CM procedure code for surgical repair of gastroschisis. Infants were categorized as non-Hispanic or Hispanic and Hispanics were sub-divided into Mexican, Puerto Rican, Cuban, and other. Mothers were further classified as US-born or foreign-born. Infants of foreign-born mothers whose country of birth did match her reported ethnicity were excluded. Descriptive statistics were calculated for maternal age, race and ethnicity, infant sex, and parity. Logistic regression was used to calculate odds ratios (OR) and their associated 95% confidence intervals (95% CI).

Results: During the study period, there were 1,216,142 live births to Florida residents and 397 gastroschisis cases (3.3/10,000 live births). Risk of having an infant with gastroschisis decreased with increased maternal age. Women less than 20 years of age had the highest risk and were nearly six times as likely to have an infant with gastroschisis (OR=5.85, 95% CI: 4.35-7.79) than women 25 to 29 years of age. When compared to non-Hispanics, Hispanic women were less likely to have an infant with gastroschisis (OR: 0.72; 95%CI: 0.56-0.93). There was a great deal of heterogeneity among the Hispanic ethnicities. Regardless of ethnicity, offspring of foreign-born mothers had lower prevalence rates of gastroschisis than their US-born counterparts. However, the association between Hispanic ethnicity and gastroschisis disappeared following adjustment for maternal country of birth, maternal age, and parity (OR=1.02, 95%CI=0.76, 1.37).

Conclusion: Our data confirm that young maternal age is a significant risk factor for gastroschisis and suggest that maternal ethnicity may not be an important risk factor for gastroschisis in Florida. Additional studies are needed to confirm these results and adequately describe the risk factor profile for infants born with gastroschisis.

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

C3.1 Arkansas Center for Birth Defects Research and Prevention

Gastroschisis and Mode of Delivery: National Trends and Evaluation of Outcomes, 1991-2005

T. M. Bird, J. M. Robbins, E. R. Kokoska, M. A. Cleves, J. A. Reading, C. A. Hobbs

Objective: Gastroschisis is a severe abdominal wall defect that occurs in 1 of every 2,500 live births. The incidence of gastroschisis is rising in the US and other countries. It is important to understand the hospital presentation and effectiveness of treatments for this disorder. There is still no consensus as to whether cesarean delivery (CD) or vaginal delivery (VD) is the preferred mode of delivery for infants with gastroschisis. Despite the lack of evidence that CD if preferable to VD, there is evidence that rates of CD for infants with gastroschisis are increasing. Our objective is to use national hospital discharge data to evaluate the association between mode of delivery of infants with gastroschisis and outcomes including mortality, complications, and length of stay.

Methods: Data for this study come from the Nationwide Inpatient Sample (NIS) produced by the Agency for Healthcare Research and Quality (AHRQ). The NIS contains all discharge records from a sample of hospitals that approximates a 20% stratified random sample of all hospitals in the US. Data from years 1991-2005 were included in the study. Infant records were selected for the study if they included both an ICD-9-CM diagnosis code of 756.7 (anomalies of the abdominal wall) and an ICD-9-CM procedure code of 54.71 (repair of gastroschisis). Only infants who received their surgical repair in the birthing hospital were included in the analysis.

Results: Over 10,000 weighted cases (2,047 unweighed cases) were included in the study. The rate of gastroschisis increased from 2.02 per 10,000 live births in 1991-1993 to 4.10 per 10,000 live births in the 2003-2005. The cesarean delivery rates for infants with gastroschisis increased from 53.3 % in 1991-1993 to 60.0% in 2003-2005. Overall, 19.7% of gastroschisis infants had a major comorbid birth defect and 50.2% were born prematurely. Crude odds ratios, traditional logistic regression models and propensity score matched logistic regression models showed no significant difference between CD and VD in odds of mortality, necrotizing enterocolitis (NEC), sepsis, respiratory distress syndrome, intestinal surgery, staged closure, or medical complications. Parallel negative binomial regression models showed a significant reduction in LOS for infants delivered via CD (AIRR 0.94, 95% CI 0.89, 0.99). Instrumental variable analysis showed a significant increased risk of NEC for CD infants with gastroschisis (AIRR 1.26, 95% CI 1.00, 1.59).

Conclusions: Rates of gastroschisis have increased steadily over the past 12 years in the US. Although most cases of gastroschisis are isolated defects, almost one fifth have a serious comorbid defect and half are born prematurely. A small benefit in terms of decreased length of stay may be realized for infants with gastroschisis delivered via CD. There is no evidence that CD benefits infants with gastroschisis in terms of mortality, sepsis, respiratory distress syndrome, intestinal surgery, medical complications, or rates of staged closure.

C3.2 Department of Defense Birth and Infant Health Registry

Health Outcomes among Infants Born to Women Deployed in Support of the Wars in Iraq and Afghanistan

Isabel G. Jacobson, Carter J. Sevick, Tyler C. Smith, Gia R. Gumbs, Ava Marie S. Conlin, and Margaret A.K. Ryan

Background: Deployed military personnel encounter a variety of hazards that may adversely affect reproductive health. The increasing proportion of women in the US military and the potentially hazardous exposures faced during military service prompted the Department of Defense (DoD) to establish in 1998 a surveillance system for birth defects. The DoD Birth and Infant Health Registry monitors the birth and health outcomes of all DoD-sponsored babies through their first year of life. Given the upsurge in military deployments in support of the wars in Iraq and Afghanistan during the past few years, it became important to investigate whether maternal deployment was associated with adverse health outcomes in offspring.

Methods: Data from the DoD Birth and Infant Health Registry were used to ascertain health outcomes within the first year of life. The cohort for these analyses included 52,528 infants with complete demographic and occupational information born to military women during calendar years 2002 to 2004. Health outcomes were classified using ICD-9-CM codes. Using multivariable modeling, these analyses investigated whether maternal deployment during pregnancy was related to birth defects, extreme preterm or preterm birth, and malignant neoplasms in infants.

Results: Of the 52,258 infants in these analyses, 4,698 were born to mothers who deployed prepregnancy, 2,560 were born to mothers who deployed in the first trimester, 115 were born to mothers who deployed later in pregnancy, 8,075 were born to mothers who deployed after pregnancy, and 37,080 were born to mothers who did not deploy. Women deployed any time during pregnancy were not more likely to have an extreme preterm or preterm baby when compared with women deployed before or after pregnancy, and those who never deployed. Additionally, no increased risk of birth defects was found among women who deployed prepregnancy, during the first trimester, or later in pregnancy. Very few cases of malignant neoplasms were found among the infants in these analyses, and no association between malignancies and maternal deployment any time during pregnancy was observed.

Conclusions: These analyses suggest that infants born between 2002 and 2004 to military women deployed in support of the wars in Iraq and Afghanistan were not at increased risk of a major birth defect, being born preterm, or having a malignant neoplasm when compared with infants born to women deployed postnatal or never deployed.

C3.3 Florida Birth Defects Registry

Risk of Preterm Birth for Black and Hispanic Infants with Major Congenital Heart Defects

Wendy N. Nembhard, Jason L. Salemi, Melissa L. Loscalzo, Tao Wang, and Kimberlea W. Hauser

Background: Congenital heart defects (CHD) are the most prevalent birth defects and a leading cause of birth defect-related infant morbidity and mortality in the U.S. Infants with CHDs have increased risk of preterm birth (PTB) compared to infants without birth defects. Historically, non-Hispanic (NH) Blacks have increased risk of PTB while Hispanics have rates of PTB comparable to NH-Whites; however, it is unknown if this pattern of PTB is consistent for infants with specific types of CHDs. Therefore, the purpose of our study was to determine if defect-specific risk of PTB varies by maternal race/ethnicity among infants with major CHDs.

Methods: We conducted a retrospective cohort study with 14,888 singleton infants from the Florida Birth Defects Registry, born to resident NH-White, NH-Black and Hispanic women aged 15-49 from 1998-2003 and diagnosed with conotruncal, right and left obstructive or septal CHD. Data on potential confounders: maternal age, education, parity, infant birthweight, gestational age and fetal growth were taken from Florida birth records; PTB was defined as 20-36 weeks gestation. Odds ratios (OR) and *p*-values were calculated from defect-specific multivariable logistic regression models. Statistical significance was set at *p*<.002 to account for multiple comparisons.

Results: The greatest risk of PTB was for NH-Black infants with conotruncal CHD. NH-Blacks with common truncus, transposition of the great vessels and tetralogy of Fallot had increased risk of PTB compared to NH-Whites (OR=4.0, *p*<.002; OR=3.1, *p*<.002; and OR=2.3, *p*<.002, respectively). Hispanics with conotruncal CHDs had almost a two-fold risk of PTB compared to NH-Whites (*p*>.002). Among right obstructive CHDs, NH-Blacks with tricuspid valve atresia/stenosis had 4.1 times (*p*>.002) and Hispanics had a 2.7 times higher risk of PTB compared to NH-Whites (*p*>.002). For infants with left obstructive CHD, NH-Blacks with hypoplastic left heart syndrome had 2.9 times the risk of NH-Whites (*p*>.002). We observed similar patterns of increased risk for very PTB (20-31 weeks) and moderate PTB (32-36 weeks) for NH-Blacks and Hispanics with specific types of CHDs.

Conclusions: Among infants with major CHDs both NH-Black and Hispanic infants are at risk of PTB. Future research is needed to examine the etiologies of this complex relationship and its contribution to disparities in PTB.

C3.4 Hawaii Birth Defects Program

Descriptive Epidemiology of Bilateral Renal Agenesis and Dysplasia, Hawaii, 1986-2003

Mathias B. Forrester and Ruth D. Merz

Objective: One of the most serious birth defects affecting the urogenital system is bilateral renal agenesis and dysplasia (BRAD). The purpose of this investigation was to describe the epidemiology of BRAD with respect to a variety of demographic and clinical variables.

Methods: Data were obtained from a Hawaii birth defects registry and included all infants and fetuses of any pregnancy outcome with BRAD during 1986-2003. Comparisons were made between subgroups of a variety of demographic and clinical factors.

Results: Of the 73 cases of BRAD, 44% were BRA, 41% BRD, and the rest mixed renal agenesis and dysplasia or unknown status. Among live births, 100% with BRA and 48% with BRD expired within one year. Elective terminations accounted for 25% of BRA and 17% of BRD cases. The male:female sex ratio was 1.38 for BRA and 2.00 for BRD. BRAD rates were not influenced by maternal age >35 years (RR 0.57, CI 0.20-1.30). There was lower risk with female sex (RR 0.60, CI 0.36-0.99) and higher risk with multiple births (RR 3.31, CI 1.04-8.10) and lower birth weight (RR 27.93, CI 14.76-55.35) and gestational age (RR 30.46, CI 13.59-80.26

Conclusions: BRA and BRD differed with respect to pregnancy outcome and sex ratio. BRAD risk was related to sex, plurality, birth weight, and gestational age but not maternal age.

C3.5 National Birth Defects Prevention Network

Geocoding Capacity of Birth Defects Programs: Results from the National Birth Defects Prevention Network Geocoding Survey

Leslie O'Leary, Ying Wang, Russel Rickard, and Craig Mason

Background: Although birth defects surveillance programs have been monitoring time trends of birth defects for years, evaluating spatial variation of birth defects is relatively new to many programs. Geocoding, which is defined as the process of assigning geographic identifiers (i.e., latitude and longitude coordinates) to specific locations such as street addresses, is a necessary step in conducting spatial analyses. Therefore, a survey was developed and administered to obtain information regarding the geocoding capabilities of state birth defects programs.

Objective: To gain an understanding of the capacity of state birth defects programs to geocode maternal residence and to identify barriers to geocoding birth defects data.

Methods: A survey focusing on geocoding of birth defects data was developed by a subcommittee of the NBDPN Data Committee. The survey consisted of 21 questions related to geocoding of maternal residence, type of software used, barriers to geocoding, etc. In June 2007 the questionnaire was entered into SurveyMonkey, a web-based survey tool. In August 2007 an email was sent to all state birth defects program contacts including the District of Columbia, Puerto Rico, and the Centers for Disease Control and Prevention (CDC) requesting they complete the online survey.

Results: By October 2007, 39 (74%) birth defects program contacts completed the survey. Ninety-seven percent of the programs that completed the survey reported they collected data on maternal residence. The maternal residence information collected by these programs was maternal full residential street address at delivery. In addition, 24% of the programs indicated they also collected maternal residence at times other than delivery. Of the 38 programs that reported they collected maternal residence, 55% indicated that the data were geocoded to the street address level. The software most commonly used by these programs was ArcView; 70% of the programs used this software. Among the programs that reported they collected maternal address but do not geocode the data, 25% indicated "software and address referencing file not available" as a significant barrier to geocoding the data. Fifty-six percent of the programs that reported they did not currently geocode residential data planned to do so in the future (20% within six months, 30% in six months to one year, 50% in greater than one year).

Conclusion: Although nearly all birth defects programs collect residential data, many programs are not currently geocoding the data. Since geocoding is a necessary component of spatial analyses, which are used to detect potential clusters of birth defects, leveraging resources to overcome the barriers that prevent programs from geocoding is important.

Disclaimer: The findings and conclusions in this presentation are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention.

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

Requirements for Reliable Estimation of Prevalence of Birth Defects

CJ Alverson, Cara Mai, and Adolfo Correa

Background: One of the objectives of birth defects surveillance programs is to estimate the baseline prevalence of specific birth defects. However, the rarity of specific birth defects poses challenges for such estimation and for monitoring changes from the baseline prevalence. We describe the minimum birth volume required to reliably detect birth defects and to estimate the prevalence of a birth defect for a given level of precision. We also outline some general requirements for reliable prevalence estimation.

Objectives: We examine the dependence of a surveillance system's sensitivity and ability to precisely estimate birth defects prevalence on its total live birth volume, and suggest methods in recognizing and estimating the prevalence of birth defects.

Methods: We examine the sensitivity of a surveillance system in terms of the least likely birth defect for which we expect one or more cases to be detected. We computed both simulated and actual performance of the system in capturing birth defects whose prevalence levels are below the minimum sensitivity of the system. We estimated the birth volumes required to yield prevalence estimates that differ from the true prevalence by specified levels of precision at selected levels of confidence.

Results: In examining state birth defects programs, we found that reported annual coverage ranged from 6,500 to 377,374 LB, with corresponding minimum sensitivities ranging from .03 to 1.54 cases per 10,000 LB. For example, MACDP reports coverage of 51,676 LB in 2003, with minimum sensitivity for this system at .19 cases per 10,000 LB. The system will have difficulties in reliably capturing any defect with a true prevalence of less than .19 cases per 10,000 LB. To test this, we simulated the capture of a birth defect with true prevalence 1 case per 1,000,000 LB. As expected, the system missed the defect on an annual basis, except at years 1973(.40), 1980(.36) and 1996(.24), versus the true prevalence of .01 cases per 10,000 LB. A pooled estimate using all years from 1968 through 2003 is approximately .024 cases per 10,000 LB. Estimates of required birth volumes for estimating the prevalence of some birth defects are presented. For example, when the true prevalence is 1 case per 10,000 LB, the required LB volume is 4268 births for precision at 300% of true prevalence, 6146(250%), 9603(200%), 17,072(150%), 38,412(100%), 68,288(75%), 153,649(50%), 614595(25%) and 3,841216(10%). Additional estimates of expected precision are presented for selected state birth defects surveillance programs.

Conclusions: As the total live birth increases, the ability of a system to detect rare birth defects increases. Maximizing live birth volume maximizes the program's minimum sensitivity, whether by increased coverage, sustained multi-year operations or enhanced case ascertainment.

We describe requirements for reliable estimation of prevalence of specific births defects, including a minimum expected prevalence and a minimum volume of births, and the implications for minimum number of years of accrued births for reporting such prevalence.

Disclaimer: The findings and conclusions in this presentation are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention.

C3.7 National Center on Birth Defects and Developmental Disabilities, CDC

Is Prior Pregnancy Loss Associated with an Increased Risk for Birth Defects?

J Kucik, CJ Alverson, A Correa

Objective: Prior pregnancy loss has been associated with higher prevalence of some birth defects such as neural tube defects and some heart defects. However, the extent to which history of prior pregnancy loss is associated with other birth defects is unclear. We investigated the association of prior pregnancy loss with the birth prevalence of several types of birth defects across maternal age groups.

Methods: Numerator cases for prevalence estimation were infants with one or more of 66 major birth defects born between 1994-2003 to women who had experienced at least one prior pregnancy and who were ascertained by the Metropolitan Atlanta Congenital Defects Program (MACDP), a population-based surveillance program that uses active case ascertainment. Denominator data for the corresponding live birth cohort were derived from Georgia vital records for the same birth years as the cases. For each defect, crude prevalence per 10,000 live births was computed by prior pregnancy loss status (0, 1+). Using no prior pregnancy loss as the referent group, Poisson regression models were used to estimate prevalence ratios (PR) and 95% confidence intervals (CI) accounting for maternal age group ($\leq$24, 25-34, 35+ years) and race/ethnicity (White, Black, Hispanic) through stratification or adjustment. Attributable fractions were calculated to determine the impact of prior loss on the prevalence of birth defects.

Results: During the period from 1994-2003, 8,787 infants with birth defects were born to women having at least one pregnancy, and 4,877 (56%) of those women had at least one pregnancy loss. The overall prevalence of birth defects among those who had experienced a prior loss was 4.6 per 100 live births compared to a prevalence of 1.7 per 100 among those who had not (PR=2.7, CI=2.5-2.8). Prior pregnancy loss was associated with a higher prevalence ($p<0.05$) for 57 of the 66 defects analyzed (PR ranging from 1.9 to 5.4). Defects showing strong associations with prior pregnancy loss included: coarctation of the aorta (PR=4.2; CI=3.0-5.9); perimenbranous ventral septal defects (PVSD) (PR=3.6; CI=2.9-4.5), hypospadias (PR=3.4; CI=3.0-3.8), clubfoot (PR=3.3; CI=2.7-4.1), and diaphragmatic hernia (PR=3.2; CI=2.0-5.1). Increasing maternal age was associated with an attenuation of this effect for choanal atresia, PVSD, atrioventricular septal defects (without Down syndrome), and longitudinal limb reduction defects. Increasing maternal age was not significantly associated with a modification of the pregnancy loss effect on prevalence for any defects. Among the study population, 35% of all infants with birth defects are born to women with a history of prior pregnancy loss.

Conclusions: A maternal history of prior pregnancy loss is strongly associated with an increased prevalence for several types of birth defects. The trend of this association across maternal age groups varies in direction and magnitude with no evident consistent pattern. These findings warrant further replication to better understand the role of prior losses and to elucidate possible reasons for the maternal age effects.

C3.8 National Center on Birth Defects and Developmental Disabilities, CDC

Survival of Infants with Down syndrome in Ten Regions of the United States

Chengxing Lu, Mikyong Shin, Csaba Siffel, James E. Kucik, Lisa K. Marengo, Adolfo Correa, and the Congenital Anomaly Multistate Prevalence and Survival (CAMPS) Collaborative

Objectives: Survival of infants with Down syndrome (DS) has improved in recent years, but information on the prognostic role of maternal and infant characteristics in the United States is limited.

Methods: Infants born with DS were identified by 10 population-based birth defects monitoring programs located in Arkansas (AR; birth cohort: 1993-2002), metropolitan Atlanta (AT; birth cohort: 1979–2002), California (CA; birth cohort: 1983-2002), Colorado (CO; birth cohort: 1989–2002), Iowa (IA; birth cohort: 1983–2002), New York (NY; birth cohort: 1983–2002), North Carolina (NC; birth cohort: 1989-2002), Oklahoma (OK; birth cohort: 1994-2002), Texas (TX; birth cohort: 1996-2002), and Utah (UT; birth cohort: 1995–2002). The longest follow-up in the study was 24 years in AT, and the shortest follow-up was 7 years in TX. Deaths among affected infants were ascertained through 2003 by linkage with state vital records and the National Death Index. We used Kaplan-Meier survival analysis to estimate one-year survival probability (%) for each of the 10 regions and calculated relative survival probabilities (ratios) of infants with DS compared with infants with any birth defect in AT (birth cohort: 2002). We used proportional hazards models to estimate adjusted hazard ratios (aHR) and 95% confidence intervals (CI) in relation to birth weight (<1500, 1500-2500, >=2500 grams), presence of major heart defects (yes vs. no), and race/ethnicity (non-Hispanic Whites vs. others) in all 10 regions. We also estimated aHR and CI in relation to birth cohort (1993-2002 vs. 1983-1992) limited to three regions (AT, IA, NY).

Results: The one-year survival probability for infants with DS ranged from 89% in NC to 95% in UT. The 24-year survival probability among individuals with DS in AT was 85%. The one-year relative survival probability of infants with DS compared with infants with any birth defect in AT as a reference ranged 0.96-1.03. For all 10 regions, factors associated with an increased risk of mortality among infants with DS were low birth weight (aHR ranged 2.3-13.7 for <1500g vs. >=2500g; and 1.3-2.3 for 1500-2500g vs. >=2500g) and presence of major heart defects (aHR ranged 1.7-4.4). Compared with non-Hispanic White infants, infants of other race/ethnicity had a higher risk of mortality in AR (aHR=2.3; CI=1.3-4.1) and in NY (aHR= 1.5; CI=1.1-1.9). Within each region, the one-year survival probability increased with successive birth cohorts, except for the state of OK. Infants born in the 1993-2002 birth cohort in AT, IA, and NY had higher survival probability than those born in the 1983-1992 birth cohort (aHR ranged 0.4-0.6).

Conclusions: In this multistate study, survival of infants with DS increased over time in most of regions. Low birth weight and presence of heart defects were each associated with a 2-fold increased risk of mortality in all regions, while other race/ethnicity was associated with at least a 50% increase risk of mortality in two regions (AR, NY). Further studies are warranted to elucidate the possible reasons for the race/ethnic disparities in survival among children with DS and the possible influence of access to health services and treatment on survival.

C3.9 National Center for Birth Defects and Developmental Disabilities, CDC

Long-Term Survival of Infants with Atrioventricular Septal Defects with and without Down Syndrome in Atlanta

Assia Miller, Csaba Siffel, Chengxing Lu, Tiffany Riehle-Colarusso, Adolfo Correa

Objective: Atrioventricular septal defect (AVSD) is the most frequent congenital cardiac malformation associated with Down syndrome (DS). Survival of infants with AVSD has improved recently. However, population-based data on similarities and differences of prognostic factors among infants with AVSD alone compared to infants with AVSD and DS is limited. Is the survival probability for infants with AVSD influenced by DS, demographic factors, and clinical characteristics at birth?

Methods: We evaluated the survival of infants with all types of AVSD, either with DS (n=161) or without DS (n=152), born between 1979 and 2001, and identified through the Metropolitan Atlanta Congenital Defects Program. Deaths (n=102) were identified through 2002 by linkage with state vital records and the National Death Index. Kaplan-Meier survival probabilities were estimated. Adjusted hazard ratios (aHR) and 95% confidence intervals (CI) were calculated in relation to demographic (birth cohort, race, sex, maternal and paternal age, parity, socioeconomic status) and clinical (birth weight, gestational age, method of delivery, presence of multiple defects, time of first diagnosis, severity of heart defect) characteristics.

Results: Among children with AVSD, those with DS had a better overall survival probability (66%) than children without DS (47%) (p<0.001). Infants with DS had mostly moderate types of AVSD (71%). After adjusting for preterm birth, severity of heart defect, and presence of major noncardiac defects, we found that survival of children with AVSD is not influenced by presence of DS and demographics. However, survival was poorer among children with severe heart defects (aHR=7.95, CI: 3.87-16.35), preterm birth (aHR=1.59, CI: 1.03-2.45), and presence of major noncardiac malformations (aHR=1.73, CI: 1.10-2.71).

Conclusions: Children with AVSD and DS have a better survival than those without DS. Among the factors examined, factors associated with poorer prognosis include preterm birth, severity of heart defect, and presence of major noncardiac malformations. Elucidation of the variation in survival by type of heart and major noncardiac defects among infants with AVSD merits further investigation. Our findings may be helpful to clinicians, health care planners, and parents in assessing the long-term prognosis of infants with AVSD with and without DS.

C3.10 National Center on Birth Defects and Developmental Disorders, CDC

Effectiveness of National Death Index for Ascertainment of Infants and Children: Example of Atlanta Spina Bifida and Down Syndrome Deaths

R Miller, L. Besser, A Correa

Objective: The National Death Index (NDI) is frequently used to obtain mortality data for a variety of follow-up studies, but the effectiveness of NDI matching for children has not previously been reported. Because many children may lack a social security number, it may be difficult to match to death certificates for these individuals. Some studies have assessed the validity of the NDI for purposes such as cancer mortality and underlying cause of death, but no studies have assessed its validity for infant and child death. This study will use Down syndrome and spina bifida cases from Metropolitan Atlanta to measure the validity of the NDI matching system.

Methods: The Metropolitan Atlanta Congenital Defects Program (MACDP), a population-based birth defects surveillance system, abstracted spina bifida and Down syndrome deaths from 1979-2002. We then used the National Death Index to request death matches for these cases. The NDI assigns a probability score to all death matches. For our purposes, a high probability match was ≥0.30 and a low probability match was 0.20-0.29. Death certificates were then requested from Georgia Vital Records and 28 states nationally. Matches were compared with several variables including name, date of birth, date of death, race, and sex. In addition, for low probability matches we analyzed which variables were discordant between the data sets.

Results: High probability matches were requested for 162 cases. Low probability matches were requested for 91 cases. All of the high probability and low probability death certificates requests were granted, except one low probability death certificate in New Jersey. In addition, 18 (20%) of the low probability case requests were returned as no record was found, leaving 73 low probability matches. Of the high probability death cases, we were able to conclude a match in all cases (100%) between MACDP, NDI, and the death certificate. Only a small percentage (2%) of the high probability matches contained discordant information on variables such as date of death, race, or name; however, enough variables matched to be determined a true match. Of the low probability matches, none of the cases could be identified as a true match between MACDP, NDI, and the death certificate. For low probability matches, 46 (63%) cases matched on first name and 29 (31.8%) matched on last name. None of the cases matched on date of birth and 2 (2.7%) cases did not match on date of death. Lastly, 38 (52%) cases matched on race and 38 (52%) of cases matched on gender.

Conclusions: This is, to our knowledge, the first study to validate the NDI matching system for infant and child death cases. Results showed that high probability NDI matches were indeed true matches when compared with death certificate information and low probability matches were not true matches. Researchers should use NDI low probability matches with caution for their studies on infants and children. Based on our results, researchers should have confidence in the NDI system for high probability matches.

C3.11 National Center on Birth Defects and Developmental Disabilities, CDC

Prevalence of Major Birth Defects in Metropolitan Atlanta, 1978-2003

Lisa Rynn, Janet Cragan, Adolfo Correa

Background: Although major structural birth defects are a significant contributor to infant mortality and morbidity in the United States, published information on the recent population-based prevalence of all major birth defects is limited. This study seeks to determine the population-based prevalence of major birth defects in the metropolitan Atlanta region and to examine the variation in prevalence by selected infant and maternal characteristics.

Methods: The Metropolitan Atlanta Congenital Defects Program (MACDP) is an active population-based birth defects surveillance system, which has continuously monitored the prevalence of major structural birth defects in the central five-county metropolitan Atlanta region. Study cases were infants with major birth defects born between 1978 -2003 in Atlanta and ascertained by MACDP. Information on the denominator for this birth cohort was obtained from vital records. Prevalence of all major birth defects per 100 live births was determined by birth cohort (1978–87, 1988–96, 1997–2003) and stratified by sex of the infant (reference=female), birth weight (<2500 grams, >=2500 grams [reference]), gestational age (20-36 weeks, >=37weeks [reference]), maternal age (<35 years [reference], >=35 years), and maternal race/ethnicity (White [reference], Black, Hispanic). Prevalence estimates between strata of each of these variables were compared using prevalence ratios (PRs) and 95% confidence intervals (CI).

Results: The overall prevalence of major birth defects has remained relatively stable from 1978 to 2003, with rates of 2.77 per 100 and 2.53 per 100 live births for these respective years. The overall temporal stability of the prevalence of birth defects was evident within strata of the variables examined. However, stratified analyses revealed a higher prevalence among infants with a birth weight of less than 2,500 grams (PR=2.99; 95%CI=2.88 – 3.10), 20-36 weeks gestation (PR=2.78; 95% CI=2.68 – 2.88), male (PR=1.27; 95% CI=1.25 – 1.29) and born to women age 35 years or older (PR=1.29; 95% CI=1.24 – 1.35). The prevalence of birth defects was lower among Blacks (PR=0.94; 95% CI=0.93– 0.96) and among Hispanics (PR=0.87; 95% CI=0.83 – 0.91. The prevalence of birth defects among offspring of White women 35 years increased over time (test for trend: p<0.05).

Conclusions: The prevalence of major structural birth defects in metropolitan Atlanta remained relatively stable during 1978 – 2003. However, the prevalence of birth defects did vary among subgroups of infants, with a higher prevalence observed among low birth weight or preterm births, males, and among offspring of women 35 years of age and older. Infants of major minority groups showed a lower prevalence of birth defects. These findings suggest that monitoring of trends of birth defects may be more informative when stratified by these infant and maternal characteristics.

C3.12 National Center on Birth Defects and Developmental Disabilities, CDC

Down Syndrome Prevalence among Children in Ten Regions of the United States

Mikyong Shin, James E. Kucik, Chengxing Lu, Csaba Siffel, Adolfo Correa and the Congenital Anomaly Multistate Prevalence and Survival (CAMPS) Collaborative

Objectives: Although Down syndrome (DS) is one of the most frequently reported birth defects among live births, the prevalence of DS among older children in the United States (U.S.) is unknown. We estimated the prevalence of DS among children in 10 U.S. regions and investigated variations in prevalence by age-group, region, race/ethnicity, infant sex, and presence of congenital heart defects.

Methods: Infants born with DS were ascertained by 10 population-based birth defects monitoring programs located in Arkansas, metropolitan Atlanta (five central counties), California (eleven counties), Colorado, Iowa, New York (New York city excluded), North Carolina, Oklahoma, Texas and Utah. Linkages with the National Death Index and state vital records were used to determine vital status as of 2002. To estimate yearly prevalence among children with DS, the numerator was derived from the number of children living with DS and the denominator was derived from respective U.S. Census population estimates. Because Hispanic ethnicity was not available in U.S. Census population estimates until 1990, we estimated prevalence by race/ethnicity from 1990–2002. Poisson regression was used to examine trends in the 3-year prevalence among children with DS by four-year age groups (0-3, 4-7, 8-11, and 12-15 year olds). To provide the most current estimates of total DS prevalence among children, we estimated point prevalence among children 0-19 year olds with DS as of July 1, 2002. Point prevalence ratios (PR) and 95% confidence intervals (CI) were estimated by race/ethnicity, sex, and presence of a congenital heart defects across the 10 regions.

Results: DS prevalence among children increased significantly among all age groups from 1990 to 2002 and was consistently higher among the younger age groups than among the older age groups. In July 2002, DS point prevalence (per 10,000 population) across the 10 regions ranged from 8.7-12.5 among 0-3 year olds, 7.5-12.0 among 4-7 year olds, 6.6-12.6 among 8-11 year olds, and 6.5-8.8 among 12-15 year olds. Among children under 4 years, the prevalence was lowest in Arkansas (8.7), and similar in the other nine regions (10.3-12.5). Compared with 0-19 year old non-Hispanic Whites, 0-19 year old non-Hispanic Blacks had a lower prevalence (PR=0.72, CI=0.67-0.76) and Hispanics had a higher prevalence (PR=1.21, CI=1.16-1.26). DS prevalence was lower among males than among females (PR=0.90, CI=0.86-0.93). The prevalence of children with both DS and a congenital heart defect was lower than the prevalence of children with DS without a congenital heart defect (PR=0.83, CI=0.80-0.86), and this prevalence ratio decreased among older age groups (p<0.0001).

Conclusions: The prevalence of DS consistently increased over time, but decreased with increasing age. Prevalence estimates varied by region, race/ethnicity, infant sex, and congenital heart defect status suggesting possible variations in prevalence at birth and in survival by these characteristics. Further studies are needed to elucidate the reasons for such variations in DS prevalence and to determine whether health services are meeting the needs of an increasing number of children with DS.

C3.13 National Center on Birth Defects and Developmental Disabilities, CDC

Spina Bifida Prevalence among Children in Ten Regions of the United States

Mikyong Shin, James E. Kucik, Chengxing Lu, Csaba Siffel, Adolfo Correa and the Survival and Congenital Anomaly Multistate Prevalence and Survival (CAMPS) Collaborative

Objectives: Little is known about the prevalence of spina bifida (SB) among children of different age groups due to the lack of population-based registries of affected children beyond infancy. We estimated the prevalence of SB among children in 10 regions of the United States (U.S.) and investigated variations by age group, region, race/ethnicity, sex, and lesion site of SB.

Methods: Infants born with SB were ascertained by 10 population-based birth defects monitoring programs located in Arkansas, metropolitan Atlanta (five central counties), California (eleven counties), Colorado, Iowa, New York (New York city excluded), North Carolina, Oklahoma, Texas and Utah. We excluded suspected SB cases, and also SB in association with anencephaly. Linkages with the National Death Index and state vital records were used to determine vital status as of 2002. To estimate yearly prevalence of children with SB, the numerator was derived from the number of children living with SB, and the denominator from respective U.S. Census population estimates. We estimated prevalence starting from 1990 because Hispanic ethnicity was not available in U.S. Census population estimates until 1990. The trends of 3-year prevalence among children with SB by age group (0-3, 4-7, 8-11, and 12-15 year olds) from 1990 to 2002 were examined using Poisson regression. To provide the most current estimates of SB, we estimated point prevalence among children 0-19 years old with SB as of July 1, 2002. Point prevalence ratios (PR) and 95% confidence intervals (CI) were estimated by race/ethnicity, sex, and lesion site (cervicothoracic, lumbosacral).

Results: The overall SB prevalence among children showed a slight decreasing trend among all age groups over time. One exception was that among children 0-3 years old, the yearly SB prevalence remained stable in Iowa from 1998 to 2002. In July 2002, the SB point prevalence (per 10,000 population) across the 10 regions ranged from 1.8-4.6 among <4 year olds, 2.1-4.6 among 4-7 year olds, 1.8-3.5 among 8-11 year olds, and 2.9-3.8 among 12-15 year olds. The prevalence of SB was higher among females than among males (PR=1.12, CI=1.05-1.20). Compared with 0-19 year old non-Hispanic Whites, 0-19 year old non-Hispanic Blacks had a lower point prevalence (PR=0.62, CI=0.54-0.70) while 0-19 year old Hispanics had a higher point prevalence (PR=1.13, CI=1.05-1.22). The prevalence of children with lumbosacral SB was higher than the prevalence of children with cervicothoracic SB (PR=6.36, CI=5.60-7.22).

Conclusions: The prevalence of SB among children varies by race/ethnicity, sex, and SB lesion site suggesting possible variations in prevalence at birth and/or in survival by these characteristics. Information on age-group specific prevalence estimates could be useful in assessing the resources needed to treat each age group more effectively in defined communities.

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C3.14 National Center on Birth Defects and Developmental Disabilities, CDC

Improving Survival of Infants with Biliary Atresia in Atlanta

Csaba Siffel, Chengxing Lu, Assia Miller, Richard Olney, and Adolfo Correa

Background: Biliary atresia (BA) is a progressive condition manifested shortly after birth that without surgical intervention leads to early death. It has been suggested that survival of infants with BA has improved in recent years, but population-based information on long-term survival and prognostic significance of demographic and clinical characteristics at birth is limited. We aimed to examine the long-term survival of infants with BA and whether demographic and infant clinical characteristics influence such survival.

Methods: The study cohort consisted of infants with extrahepatic BA (n=75) born between 1979 and 2003 and identified through the Metropolitan Atlanta Congenital Defects Program. Vital status was ascertained through 2004 through linkage with state vital records and the National Death Index (19 deaths). We estimated Kaplan-Meier survival probabilities stratified by birth period, sex, race, maternal and paternal age, socioeconomic status, birth weight, gestational age, method of delivery, pediatric hospital admission, presence of multiple major defects, and time of diagnosis. Adjusted hazard ratios (aHR) and 95% confidence intervals (CI) were estimated using Cox proportional hazards models.

Results: The overall survival probability of infants with BA (71%) significantly improved over time: 1979-1984, 40%; 1985-1990, 72%; 1991-1996, 87%; 1997-2003, 89% (test for trend: p=0.0036). Infants born in recent time periods (1994 and later) had better survival than those born before 1994 (aHR=0.25, CI 0.82-0.76). Time of diagnosis seemed to affect survival: survival was better when the diagnosis was made less than 60 days after birth (aHR=0.34, CI 0.13-0.84). None of the other factors examined showed a significant effect on survival.

Conclusions: Survival probability of infants with BA improved during the last three decades in metropolitan Atlanta. Children born in recent years and affected by this life-threatening condition have a good long-term prognosis after early diagnosis and subsequent portoenterostomy operation or liver transplantation but information on surgical interventions is limited in our data. Improved survival may also be related to improved follow-up of patients including prophylactic medication to prevent recurrence of cholangitis and cyst formation after surgical treatment, but this information cannot be discerned from our data. Time of diagnosis may be an important prognostic factor but further studies with larger sample sizes are needed to corroborate this finding.

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C3.15 National Center on Birth Defects and Developmental Disabilities and Michigan Birth Defects Registry

Birth Defects and Genetic Disorders among Arab Americans—Michigan, 1992–2003

Emad Yanni, Glenn Copeland, Richard Olney

Background: Hereditary and metabolic disorders are responsible for a substantial proportion of infant morbidity and mortality in Arab countries. Michigan has the second largest Arab-American community in the United States after California. The purpose of this study was to estimates of rates of major birth defects and congenital endocrine, metabolic, and hereditary disorders among children born to Arab Americans in Michigan.

*Methods***:** The Michigan Birth Defects Registry (MBDR) is a statewide, population-based surveillance system that receives reports of birth defects and genetic disorders from hospitals, cytogenetics laboratories, and genetic counseling centers. The MBDR includes information on parents' country of birth and ancestry. Data from 1992 through 2003 were extracted from the MBDR and linked to birth certificate data. Birth prevalences were estimated in offspring of Michigan women of Arab ancestry for 21 major categories of birth defects and 12 congenital endocrine, metabolic, and hereditary disorders. The prevalences for children of Arab Americans mothers were compared with those for children of non-Hispanic, non-Arab white mothers in Michigan and for all non-Arab children born in Michigan during the study period.

Results: During the study period, there were 36,830 live births to mothers of Arab ancestry out of 1,184,587 live births to non-Hispanic white mothers in Michigan. Of these, the MBDR received reports of 2,374 children of Arab ancestry with birth defects. Of all mothers with Arab ancestry, 68.8% reported that the father also had Arab ancestry. Certain birth defects were slightly more prevalent among Arab Americans compared with all Michigan and non-Hispanic whites, but the difference in rates was not statistically significant: anophthalmia/microphthalmia, esophageal atresia/tracheoesophageal fistula, lower limb reduction defects, Down syndrome, and trisomy 18. Other structural birth defects were generally lower in prevalence in Arab Americans than among non-Hispanic whites and all non-Arab Michigan births, but these differences were statistically significant only for two categories of defects: cleft lip with or without cleft palate (3.53 and 10.69/10,000 live births respectively, for Arab Americans and Non-Hispanic white) , and the combined category for two abdominal wall defects: gastroschisis or omphalocele (0.81 and 4.04/10,000 live births respectively). Compared with other non-Hispanic white children in Michigan, Arab American children had higher frequencies of glucose-6-phosphate dehydrogenase deficiency and increased rates for three categories of metabolic disorders: maple syrup urine disease and other branched-chain aminoacidopathies, medium chain acyl-CoA dehydrogenase deficiency and other specified metabolic disorders, and organic acidemias and other acidoses. The rates of thalassemia (1.36 versus 0.29/10,000 live births respectively) and sickle cell disease (1.36 versus 0.78 /10,000 live births respectively) were also higher in Arab Americans than in other non-Hispanic whites, but the difference was only statistically significant for thalassemia.

Conclusions: The study highlights the increased prevalences of specific categories of genetic disorders among Arab Americans in Michigan. The data suggest the need for culturally sensitive health care and genetic counseling in Arab populations in the United States, to provide appropriate clinical care and to interpret disparities in health care use due to structural birth defects and other congenital conditions. .

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C3.16 New York State Congenital Malformations Registry

Prevalence of Selected Birth Defects in New York State, 1999-2004

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

Background: There are no population-based national data on birth defects except for neural tube defects (NTD), despite it being a leading cause of infant mortality and a major cause of mortality and morbidity throughout childhood. Data on birth defect prevalence generally come from birth defects registries maintained by specific states. Recently the Centers for Disease Control and Prevention (CDC) and the National Birth Defects Prevention Network (NBDPN) developed national prevalence estimates for 21 selected major birth defects, based on data for the years 1999-2001 from 11 state birth defects registries which used active ascertainment.[1] The national estimates are useful and can be used as a standard for comparisons among registries, for health care planning and to evaluate interventions such as folic acid. In this presentation, the live birth prevalences of the population-based New York State Congenital Malformations Registry (CMR) are compared with the national prevalence estimates for 21 selected birth defects.

Methods: CMR cases with 21 birth defects for the birth years 1999-2004 were selected. The 21 defects were chosen because they are recognizable at or shortly after birth and they are likely to be ascertained similarly across states. New York State live births for the years 1999-2004 were used for calculating the prevalence.

Results: The prevalence of the 21 selected defects was higher for the years 2002-2004 compared to the years 1999-2001. The CMR prevalences for the years 2002-2004 are equal to or higher than the lower boundary of the actual range of the 11 active registries (birth years 1999-2001) for 13 of the 21 defects (bold prevalences) and 4 of the defects are equal to or higher than the lower 95% Confidence Interval (CI) (boxed prevalences). The prevalences are generally higher for upstate New York State excluding New York City than for New York City; 17 defect prevalences are equal to or higher than the lower boundary of the actual range of the 11 registries and 7 are equal to or higher than the lower 95% CI, compared to 12 and 3, respectively, for New York City.

Conclusions: The increase in prevalence for the years 2002-2004 compared to 1999-2001 can be attributed to the implementation of a web-based data reporting system and staff on-site hospital audits beginning in 2002. The interpretation of differences among registry prevalences is difficult. The lower prevalences of the CMR for NTD is most likely due to the lack of reports on terminations as termination rates for NTDs are high. Lower prevalences for anophthalmia/microphthalmia might occur as some of these children have multiple defects and other defects may be reported but not the anophthalmia/microphthalmia. Preliminary data from 2005 shows an increase in anophthalmia/microphthalmia which could be the result of the on-site audits. The lower prevalence for cleft lip with/without cleft palate is difficult to explain. There has been little variation in the prevalence since 1983 and it is an easily identified condition. There is also a wide variation within New York State itself from 5.3 in New York City to 8.5 in another region. CMR staff will continue their efforts to improve reporting and will continue to track our progress using the NBDPN national prevalence estimates.

C3.17 North Carolina Birth Defects Monitoring Program and North Carolina Folic Acid Campaign

Prevalence of neural tube defects in North Carolina, 1995/1996 to 2004/2005

Amy Mullenix, Jennifer Stock, Robert E. Meyer

Background: Daily folic acid supplementation can reduce the incidence of neural tube defects (NTDs) by up to 70% and is recommended by the U.S. Public Health Service for all women of child-bearing age. In North Carolina, initial public health education campaign efforts focused on western North Carolina, where the NTD prevalence was 50 percent higher than the state average. Interventions have now been expanded to target Spanish-speaking women in North Carolina because of the higher prevalence of NTDs among Hispanics, more than double the state average.

Methods: NTD data from the North Carolina Birth Defects Monitoring program were examined by perinatal region and ethnicity from 1995/1996 to 2004/2005.

Results: The North Carolina birth prevalence of NTDs was 9.95 per 10,000 live births in 1995/1996. In 2004/2005 the prevalence was 6.01 per 10,000 live births, a decrease of approximately 40 percent from 1995/1996. The pattern followed a general downward trend over time, with a slight increase in 2003. This decline is consistent with downward NTD prevalence trends seen in other states. Of note, in western North Carolina, the NTD prevalence decreased by approximately 81 percent between 1995/1996 and 2004/2005 from 13.58 to 2.52 per 10,000 live births. The Hispanic prevalence statewide was 19.94 in 1995/1996 and 9.00 in 2004/2005 (a decrease of about 55 percent), following a similar downward trend as the overall prevalence.

Conclusions: The drop in NTD prevalence in western North Carolina between 1995/1996 and 2004/2005 greatly exceeded state and national declines. The causes of this precipitous drop are unclear, as food fortification and an intensive public health education campaign in North Carolina overlapped. The campaign utilizes several components that likely combine to have a synergistic effect on multivitamin-taking behavior: distribution of free vitamins in local health departments, media advertising, health care provider education, and lay health advisor education among women. Similar culturally-adapted programs are now being used with Spanish-speaking women in an attempt to lower the NTD prevalence among this population.

C3.18 Seoul National University Hospital

Discordant Newborns have a Higher Rate of Major Anomalies than Concordant ones in Dichorionic Twins

Kyung Joon Oh, Jong Kwan Jun

Background: The incidence of congenital anomalies is appreciably increased in multifetal pregnancy. As we know, smaller twins and discordant twins are known to be even higher risk factors for congenital anomaly. However, there are paucity of data about the relationship between concordance and size of twin. The purpose of this study was to assess the impact of discordance and size in a pair on the incidence of congenital anomaly in twin pregnancies.

Methods: We studied a total of 842 dichorionic (DC) newborns that were born in our institute from Jan 2000 to Jun 2007. Chorionicity was determined by gender and histologic examination of placenta. Discordance was defined as 20% or more of weight difference in a pair. There are 343 pairs of concordant group and 78 pairs of discordant group. Each group was subdivided into smaller infants and heavier newborns according to birth weight. Parametric and nonparametric methods were used as appropriate for statistical analysis.

Results: Among 842 DC infants, 31 neonates (3.7%) had major congenital anomalies. Discordant infants had a higher rate of major anomaly than concordant newborns [9.6% (15/156) vs. 2.3% (16/686), p<0.001]. In both groups, major congenital anomalies were more common in smaller twins than heavier co-twins, but it was not statistically significant [12.8% (10/78) vs. 6.4% (5/78), NS; 2.6% (9/343) vs. 2.0% (7/343), NS, respectively]. Table shows increased tendency of congenital anomaly among 4 groups

	Concordant		Discordant	
	Heavier	Smaller	Heavier	Smaller
Major anomaly	7/343 (2.0%)	9/343 (2.6%)	5/78 (6.4%)	10/78 (12.8%)
OR (96%CI)	Reference	1.29 (0.48-3.51)	3.27 (1.01-10.59)	7.02 (2.59-19.08)

Conclusions: Birth weight discordance was found to be an important predictor of major congenital anomaly in DC twin gestations. Even heavier newborns in discordant twins have an increased risk of congenital anomalies compared to concordant twins. Therefore, discordant twin requires careful surveillance for congenital anomaly in both fetuses.

C3.19 Texas Birth Defects Epidemiology and Surveillance Branch

Impact of Differing Texas-Mexico Border Definitions on Birth Defect Prevalence, 1999-2004

Mark Canfield, Lisa Marengo, Amy Case

Objective: The Texas Birth Defects Registry is an active, statewide surveillance system which covers all pregnancy outcomes (live births, fetal deaths, and elective pregnancy terminations). Texas shares a 1,255 mile border with Mexico; this is the largest expanse of Mexican border in the United States. There are four different definitions of what constitutes the Texas: Mexico border because of geopolitical considerations. The definitions include areas of varying numbers of counties (7 to 43). The purpose of this study was to describe the effect on birth defect prevalence of the various definitions of the Texas-Mexico border among >2.2 million live births in Texas, 1999-2004.

Methods: An analysis for the four border county definitions was conducted for the 49 selected birth defects commonly reported in the Birth Defects Registry Annual reports. The prevalences and 95% confidence intervals were compared to the "standard" border definition historically utilized by the Birth Defects Registry of the 14 Texas counties adjoining Mexico.

Results: In Texas for delivery years 1999-2004, the most prevalent birth defect categories were heart defects (ventricular septal defect, patent ductus arteriosus, and atrial septal defect) as well as hypospadias. This was found to be equally true for all border definitions. No significant statistical variation was seen between three border definitions; however, the border definition with the largest number of counties and extending away from the border displayed some significantly statistically different prevalences.

Conclusions: Three definitions of border county are similar in both demographic distribution as well as birth defects prevalence. The fourth and geographically largest definition encompassing 43 counties was found to have statistically significant differences from the standard definition in birth defect prevalences. This border definition also varies in its racial/ethnic composition. The birth defects of statistical significance are all associated with racial-ethnic differences. Based on these findings, the 14 county border region historically utilized by the Birth Defects Registry is shown to be representative of this important international border region. This is important information to have, because of occasional requests to have birth defects analyzed data according to a different geographic area, which requires additional work.

C3.20 Washington Birth Defects Surveillance System

Gastroschisis Cluster Investigation in Southwest Washington, July 2005 to April 2007

Katherine Hutchinson and Cathy Wasserman

Background: The prevalence of gastroschisis, a congenital anomaly of the abdominal wall, has been increasing significantly over the past few decades; however very little is understood about the etiology of gastroschisis and why the prevalence is increasing. In September 2006, the Southwest Washington regional perinatal center contacted the Department of Health to report a large number of gastroschisis cases diagnosed within the past year. The regional perinatal center receives high-risk pregnancy referrals from 8 surrounding counties. Cases were identified by the time frame of diagnosis reported by the perinatal center (Jan. 2005 through Dec. 2006), which resulted in deliveries between July 2005 and April 2007.

Methods: We confirmed cases through abstraction of medical records. We followed up with other perinatal practices, all level III neonatal surgical centers in Washington that perform gastroschisis repair, and vital records to ascertain additional cases. We calculated prevalence rates, and the baseline rate was determined from the most recent national estimate reported in the literature. We also determined if rates of gastroschisis were elevated in other areas of the state.

Results: A total of 34 cases of gastroschisis were delivered between July 2005 and April 2007 to residents of the clinic referral area. The rate of gastroschisis during this time period was 9.8/10,000 live births, which was 2.6 times the expected rate. The rate of gastroschisis was highest in 2006 (11.9/10,000). Twenty-three of the 34 cases were residents of one of two counties. Rates of gastroschisis were 3.4 times and 6 times the expected rate in these two counties. Significantly elevated rates were not observed in counties outside the clinic referral area.

Conclusions: This investigation found that the rate of gastroschisis was elevated approximately 2-3 fold in the clinic referral area. Few risk factors have been identified in the literature and our investigation did not yield any possible exposures. This is the second reported cluster from the same clinic in the past 10 years, and continued and frequent monitoring of gastroschisis is warranted for the Southwest Washington area.

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

C4.1 Colorado Responds to Children with Special Needs

Knowledge and Consumption of Folic Acid Working to Reduce Neural Tube Defects in Colorado

Kirk Bol, Rickey Tolliver, April Montgomery, Russel Rickard

Objective: Neural tube defects (NTDs) are birth defects of the central nervous system, including spina bifida and anencephaly. The consumption of folic acid, a B vitamin, prior to pregnancy has been shown to prevent a substantial proportion of these NTDs. In 1992, the US Public Health Service recommended that all women of child-bearing age who are capable of becoming pregnant consume 400micrograms of folic acid daily through improved dietary habits, fortified foods, or dietary supplements. The US Food and Drug Administration mandated fortification of the US flour and enriched grain supply with 140 micrograms of folic acid per 100 grams of grain in 1998. The objective of this study is to measure the rates of NTDs and the knowledge and consumption of folic acid in Colorado before and after fortification.

Methods: Prevalence estimates for neural tube defects were provided by Colorado Responds to Children with Special Needs (CRCSN), the birth defects registry. Women's knowledge of folic acid in the prevention birth defects and consumption of the recommended daily amount was monitored by the Colorado Behavioral Risk Factor Surveillance System BRFSS) survey conducted by the Health Statistics Section.

Results: Declines in NTD rates were seen in Colorado: Between 1995-1996 and 1999-2001, rates of spina bifida declined 18% and rates of anencephaly declined 38%. Despite these declines, the rate of anencephaly increased slightly during the 2002-2005 period while the rate of spina bifida returned to the same rate as that observed during 1997-1998.

In 1998, 37 % of women age 18-44 knew that folic acid could prevent NTDs, while in 2006, that percentage had increased to only 41%. In 1998, 46 % were taking folic acid daily, a percentage unchanged in 2006. In 1998, 46% were taking folic acid daily, a percentage unchanged in 2006. Women least likely to be taking the recommend daily amount were younger, Hispanic, with fewer years of education, single, and lower income. The proportion of women in Colorado is higher than the national average. In 2005, the March of Dimes reported that nationally, of women aged 18-45 years who were aware of folic acid, 19% know that it could prevent birth defects and 33% were taking it daily.

Conclusions: Key to achieving reductions in the number of NTD-affected pregnancies is increasing the knowledge that consuming folic acid can help prevent birth defects and increasing the number of women who consume the recommended amount daily before pregnancy. In Colorado, the focus is on those groups that are least likely to consume the recommended amount of folic acid daily.

C4.2 National Center on Birth Defects and Developmental Disabilities, CDC

Health Care Expenditures of Medicaid-Enrolled Children with Spina Bifida

Djesika Amendah, Scott Grosse, Lijing Ouyang

Objective: The objective of this poster is to provide estimates of the medical expenditures or costs for publicly insured children and adolescents with spina bifida in the United States and to compare these estimates with estimated expenditures for privately insured children and adolescents.

Method: We used MarketScan Medicaid data from four states and selected individuals with spina bifida-related claims in the years 2001-2003. We restricted our sample to individuals age 17 or less who had 365 days of coverage in Medicaid in 2003 and computed their direct medical cost. These medical costs include inpatient, outpatient and drug claims expenditures.

Preliminary Results: We identified a sample of 1,921 individuals with spina bifida and 1,499,033 persons without spina bifida. This yields an administrative prevalence of 15 per 10,000. Among persons with spina bifida, 23% (443) had an inpatient admission in 2003 and they incurred 757 inpatient admissions within that year. Average total expenditure per inpatient admission was $4,764. Almost all persons with spina bifida 99% (1905) had an outpatient visit. On average, persons with spina bifida had 40 outpatient visits per year and an average total expenditure of $106 per visit. Similarly 92% of the persons in this sample (1,766) had drug claims. They incurred 37,687 drug claims and the average expenditure on a drug claim was $58.

Conclusion: The administrative prevalence of spina bifida in the Medicaid sample is much higher than 5.7 per 10,000 found in the privately insured sample for the same age range and year. This indicates the importance of including both publicly- and privately-insured children. Mean expenditures per inpatient admission and outpatient visit were lower in the Medicaid population than for privately insured children enrolled in fee-for-service plans. However, most Medicaid-enrolled individuals in this sample were covered by capitated plans. Further analysis will explore the influence of capitated plans and Medicaid reimbursement schedules compared with private reimbursements. In addition, we will compute the incremental expenditures associated with spina bifida in Medicaid-enrolled children and compare these values to privately insured children.

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C4.3 National Center on Birth Defects and Developmental Disabilities, CDC

Linking Children with a Fetal Alcohol Spectrum Disorder to Services: State Based Strategies, Challenges, and Successes

FASD Prevention Project Sites, April Montgomery, and Jacquelyn Bertrand

Background: Despite primary prevention efforts, a troubling number of children continue to be born with prenatal alcohol exposure resulting in a fetal alcohol spectrum disorder (FASD). These children often are missed by traditional systems of identification, intervention and referral since many deficits related to central nervous system dysfunction manifest after the age of early intervention programs or their FASD related problems and disabilities do not meet the criteria for traditional services (eg, intellectual deficiency or qualifying diagnosis). This poster describes efforts by seven FAS Prevention Project state grantees (representing eight states) to develop and implement systems to identify children with an FASD and refer them and their families to community based interventions and services. Challenges encountered during the project (such as lack of diagnostic capacity) and success measures will be described.

Methods: The eight states in the CDC State FASD Prevention Project were surveyed to determine capacity for identification, diagnosis, and referral to services for individuals with an FASD and their families. Information obtained included: method of linking children and family to services; scope of project catchment area; and process data (such as number of cases identified, number, percent and types of FASD diagnoses made). In addition each site provided qualitative information concerning the challenges encountered in establishing their program and successful as well as innovative responses to those challenges.

Results: Five grantees were able to establish new systems or enhance existing systems to link children with an FASD and their families to appropriate community services. Of these five grantees, one expanded a current system that links surveillance cases with services via public health nurses, two used existing networks of FASD clinics and two established new FASD clinics. The remaining two states continue to address the challenge of little or no infrastructure concerning identification of cases and privacy laws. Information to date indicates that, over 400 children were evaluated for an FASD or captured by the surveillance system ranging from 187 to 50 across sites. Of the children evaluated 132 (27.9%) were diagnosed with an FASD and 71 (15.0%) were diagnosed with FAS across sites. All families, regardless of diagnosis, were provided with information concerning their child's condition and referral to appropriate community services, including therapies, special education, financial resources and social services. Challenges described included lack of local diagnostic expertise and training (5 of 6 sites), lack of appropriate resources (4 of 6 sites), and inadequate funding (all sites). In addition, current privacy laws sometimes hinder access to birth and other records needed to make a diagnosis (2 of 6 sites).

Conclusions: Most states did not have systems in place for identification of children with an FASD and linking them and their families to services. Despite challenges, important lessons were learned concerning state needs and logistics for linking children with FASDs and their families to services. Current findings for children identified, diagnosed and referred will be presented.

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C4.4 National Center on Birth Defects and Developmental Disabilities, CDC

Effectively Communicating the Folic Acid Message: Findings from Formative Research with Spanish-Speaking Latinas

Alina L. Flores, Christine E. Prue

Background: Every year in the United States, approximately 3,000 pregnancies are affected by serious birth defects of the brain and spine, called neural tube defects (NTDs). Latinas have the highest rates of NTDs and lower levels of folic acid knowledge and consumption than women of some other ethnic groups. The aim of this research was to develop educational materials and messages to be used as part of larger efforts to lower Latinas' risk of having NTD-affected pregnancies, and to close this disparities gap.

Methods: The target audience was Spanish-speaking Latinas ages 18-34. This audience was further segmented by age, acculturation, maternal status, and multivitamin use. CDC researchers led formative research consisting of three main phases: 1) Exploratory Research, 2) Concept Testing, and 3) Testing of Draft Materials with Women and Key Gatekeepers. During phase 1, researchers conducted 90 individual interviews to test existing CDC folic acid materials and radio messages and identify which, if any, were still effective in reaching Latinas. Further, 18 focus groups were conducted in six major cities to identify factors impacting folic acid consumption.

During phase 2, draft visual concepts and radio public service announcements (PSAs) were tested with participants in 9 focus groups in three major cities. Participants were asked their likes/dislikes, initial reactions, perceived intended audience, which visual concept they felt would be most appealing to Latinas, most believable, and would most inspire them to take a vitamin.

During the final research phase, 72 individual interviews were conducted with Latinas in three major cities. Participants were shown the draft materials and listened to the radio PSAs and were asked their likes/dislikes, what they would change/would not change, and whether they felt they could do the behavior mentioned (ie, taking folic acid). Further, 50 interviews were conducted with key gatekeepers who work closely with Latinas, to assess the appeal and appropriateness for their audience and whether they could and would disseminate these materials and messages.

Results: Several main themes emerged from the formative research. Barriers to multivitamin use appear to be centered around misperceptions of folic acid as important for women once they are pregnant, fears of vitamin overdose, attitudes toward vitamins as "medication" to treat illness, vitamins as meal substitutes, and misinformation about needing a prescription to purchase vitamins. Women who already had children also had a false sense of security from having had healthy pregnancies in the past and viewing this as a guarantee of future healthy pregnancies. Finally, the theme of "planning" a pregnancy appeared to be confusing for many women.

Conclusions: Three radio PSAs and a variety of educational print materials were developed based on findings from this formative research. Radio and print media buys have been scheduled for January and February 2008. There is not a one-size-fits-all solution as to how to best reach Spanish-speaking Latinas with the folic acid message. This research highlighted the impact of multivitamin use and maternal status on Latinas' belief systems, although acculturation status did not appear to be a significant factor.

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

Birth Defects: What's in a Name?

Cara T. Mai, Assia Miller

Background and Objectives: 'Birth defect' is a common phrase, yet in recent years, some parents around the country have voiced concerns that the word 'defect' might connote a negative perception and labeling of their children. It is unclear how widespread this attitude is, and a better term has yet to surface. We seek to determine public perceptions of both the connotation of terms used for birth defects, as well as the causes of birth defects.

Methods: Five questions on terminology and perceived causes of birth defects were added to the 2007 Porter Novelli *HealthStyles* survey (4398 respondents). *HealthStyles* is an annual survey conducted as a second part of a panel mail survey sent to a nationally representative sample of adults. We prefaced the questions with an introductory paragraph: "The next few questions ask about problems present at birth that affect a baby and can result in physical or mental disabilities-even death. Examples might include cleft lip, club foot, Down syndrome, or spina bifida." These questions addressed whether the person completing the survey or a family member was born with a problem like the ones described, which phrases would be a good way to describe the types of problems listed, which phrase is their first choice for describing the problems listed, whether any phrase used may be offensive, and what might cause the types of problems described. Responders had the following phrase options: birth defects, birth conditions, birth disorders, birth anomalies, congenital anomalies, congenital disorders, congenital malformation, and adverse pregnancy outcomes. We further examined whether condition status, race, gender, income, geographical region, and education level impacted the responders' choice in selecting a preferred terminology. Chi-square tests and multinomial logistic regression were performed using SAS 9.1.

Results: The majority of respondents (35.4%) indicated that 'birth defects' would be their first choice for describing the types of problems listed, followed by 21.9% who selected 'children with special needs'. When the data were stratified by responders who said they themselves or a family member was born with the problems described (11.6%), their responses were overall statistically different (P = <.0001), but the leading choices were still 'birth defects' (28.5%) and 'children with special needs' (27.2%). Condition status, race, gender, income, and education level were significant predictors for the responders' choice in selecting a preferred terminology. When we specifically asked responders to indicate which phrases might be offensive, the top choices were 'none of the phrases listed' (37.0%), 'adverse pregnancy outcomes' (23.1%), and 'birth defects' (21.4%). Finally, the top three perceived causes of the problems listed were 'genetics or family history' (60.4%); 'mom's use of drugs, alcohol, or smoking' (49.6%); and 'beyond one's control or fate' (40.5%).

Conclusions: Although 'birth defect' is still the preferred choice, those with an affected condition favored the term less than those not affected. Continued review of the public's perception of the terms used to describe birth defects will allow us to examine changes in perceptions over time.

Disclaimer: The findings and conclusions in this presentation are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention.

C4.6 New Hampshire Birth Conditions Program

Folic Acid Knowledge, Behaviors and Beliefs: A Multivitamin Distribution Campaign in New Hampshire

Lissa Sirois, Stephanie Miller, Lisa Richards, John Moeschler

Background: During 2003-2005, the prevalence of Neural Tube Defects (NTDs) in New Hampshire was 4.2 per 10,000 live births. The NH Birth Conditions Program maintains a folic acid program targeting women of childbearing age. The March of Dimes (MOD) National Survey 1995- 2005 reports that folic acid awareness among women has reached its highest level since 1995. In 2005, 84% of women between the ages of 18-45 reported they were aware of folic acid, however only 33% of women consumed a vitamin containing folic acid, and less than 20% knew folic acid prevents birth defects. These results illustrate the need to continue awareness efforts among women of childbearing age.

Methods: Anonymous pre and post-survey data was obtained through the NH multivitamin distribution campaign conducted in 19 locations across the state: including 5 WIC nutrition agencies, 13 prenatal health centers, and 1 city health department. Surveys were collected for each woman, between the ages of 18 – 45, who chose to participate. Data consists of pre (N=1596) and post (N= 238) surveys from January 2007 through mid-November 2007. Results of a targeted effort among Hispanic women in NH were also evaluated.

Results: Approximately 15% of survey responses were Hispanic, somewhat higher than the overall distribution of Hispanic females in NH. Pre-surveys found that 26% of Hispanic women and 24% of non-Hispanic women reported taking a multivitamin with 80% and 78%, respectively, taking it daily. Over 50% of Hispanics and non-Hispanics were aware that the vitamin contained folic acid. Of all women 68% reported knowledge that folic acid prevents birth defects with little difference between ethnicity, however 76% of non-Hispanic and only 60% of Hispanic women were aware of the need to take folic acid pre-pregnancy. The most frequently reported reasons for not taking multivitamins were (1) cost, (2) unable to remember and (3) if they were specifically doctor advised. Comparing our survey to the 2004 NH BRFSS, knowledge of when to take folic acid (BRFSS 89%) and awareness of folic acid for prevention of birth defects (BRFSS 64%) is comparable, however the percentage of women who take a multivitamin with folic acid (BRFSS 50%) is dramatically different. Comparing our survey to the MOD survey indicates that NH women are more aware of the prevention of birth defects and similar in number to those consuming a multivitamin. Post-survey data indicates 82% of non-Hispanic women and 88% of Hispanics continue to take multivitamins with folic acid daily, 75% and 62% respectively, know folic acid is recommended for the prevention of birth defects, and 81% and 69% respectively, know folic acid should be started before pregnancy.

Conclusions: Targeted efforts to reach Hispanic women in NH worked. Data from this project indicates more NH women would take a multivitamin containing folic acid if it were available at lower cost or free. Hispanic women may need more education about when to take multivitamins. Findings suggest that education and distribution of multivitamins have a positive effect on knowledge, behaviors and beliefs about folic acid as prevention of birth defects.

C4.7 New York State Congenital Malformations Registry

Folic Acid Awareness and Use in New York State, 1997 – 2006

April A. Austin, John F. Oldi, Charlotte M. Druschel

Objective: In 1992, the United States Public Health Service first recommended that all women of reproductive age capable of becoming pregnant take folic acid to reduce the risk of having a pregnancy affected with a neural tube defect. From September 1996 to October 1997, the New York State Department of Health (NYSDOH) conducted an extensive educational campaign that featured NYSDOH-produced materials and collaborative efforts with health professionals, organizations and neighboring states. Evaluation of awareness and daily use of folic acid in New York State women has been conducted using survey information spanning ten years.

Methods: The optional folic acid module of the Behavioral Risk Factor Surveillance System (BRFSS) was included in New York surveys conducted in 1997, 1999, 2002, and 2006. Knowledge of the benefits of folic acid to prevent birth defects and daily use of folic acid were asked of women age 18-44 by telephone interview. Weighted proportions and 95% confidence intervals were determined for overall response and across several demographic groups to represent the entire state. SAS software (SAS Institute, Cary, NC) allowed for analysis of the complex BRFSS sample design that uses random digit dialing techniques and cluster sampling.

Results: The overall proportion of New York women with knowledge of the benefit of folic acid use has not changed significantly in ten years. In 1997, 36.4% of surveyed women knew that folic acid prevented birth defects; the proportion was 32.8%, 41.7%, and 36.8% in 1999, 2002, and 2006, respectively. The decreasing trends in knowledge in 2006 were notable for women aged 18-24, for non-Hispanic black women, and women with less than a high school education. Daily use of folic acid increased from 26.2% (95% CI: 23.3%, 29.0%) in 1997 to 41.7% (95% CI: 37.7%, 45.7%) in 1999. A non-significant decrease to 38.2% (95% CI: 34.6%, 41.8%) was seen in 2006; the questions relating to daily use were not asked in 2002. Although no declines in use from 1999 to 2006 were statistically significant, the proportion of those who used folic acid daily decreased among all demographic groups with the exception of non-Hispanic white women.

Conclusions: Based on BRFSS data, folic acid use in New York is well below the *Healthy People 2010* goal that 80% of non-pregnant women of childbearing age consume at least 400 micrograms per day. The decreases in awareness and daily use across most demographic groups for 2006 are trends that should be monitored further. Resources for continual education and outreach are needed to maintain this important public health message in all New York State communities.

C4.8 New York State Congenital Malformations Registry, Iowa Birth Defects Registry Arkansas Center for Birth Defects Research and Prevention, National Foundation for Facial Reconstruction

Organized Team Care and Services Received by Children with Oral Clefts

April A. Austin, Charlotte M. Druschel, Margaret Tyler, Paul A. Romitti, James M. Robbins, Whitney Burnett, Sara Kizelnik-Freilich, Peter Damiano

Objective: The American Cleft Palate-Craniofacial Association (ACPCA) issued their recommendations for parameters for evaluation and treatment of patients with craniofacial malformations in 1993. The fundamental principle of the recommendations included the management of patients by interdisciplinary teams of specialists who maintain clinical expertise in caring for patients with craniofacial anomalies. Team care, as outlined by the ACPCA, requires integrated case management and development of comprehensive longitudinal treatment plans. The team, responsible for providing care or making appropriate referrals for care, should coordinate the following: audiologic and otolaryngologic care, surgical care, dental care, speech-language pathology services, genetic evaluations and counseling, psychological and social services, nursing care and pediatric care. Through maternal interview, we examined whether children with orofacial clefts who were not receiving coordinated cleft care were lacking in treatments and services recommended by the ACPCA.

Methods: A telephone interview was conducted with 253 mothers of children born with cleft lip or cleft palate. The mothers were identified by the population-based National Birth Defects Prevention Study Centers in Arkansas, Iowa and New York. Mothers were asked if their children were receiving care by an organized cleft care team. Information about treatments and services received by the children and unmet need for services was collected.

Results: According to the mothers, 61 (24%) of the children age 2 to 7 years were not receiving care from an organized team. Almost 30% of the children in New York were not receiving team care compared to 26% and 16% in Arkansas and Iowa, respectively. No team care was reported for 35% of children with cleft lip only, 29% with cleft palate only, and 14% of those with cleft lip and cleft palate. Sixteen percent of children whose mothers described their condition as very severe were not enrolled in team care. Services received in the year prior to the interview were determined for speech therapy, dental care and hearing tests. Speech therapy was received by 53% of those in team care compared to 41% of those not in team care. Dental care was provided more often for those in team care (80% versus 59%) and those with team care were more likely to have had a hearing test (78% versus 60%). Forty-eight percent of the families with a child in team care had ever received genetic counseling while only 26% of those lacking team care were counseled.

Conclusions: Not all children born with orofacial clefts were receiving coordinated team care as recommended by ACPCA. Children lacking coordinated care received less comprehensive care compared to those in team care. Additionally, children who received care by organized care teams may not have received all the services deemed appropriate for a child with an orofacial cleft.

C4.9 North Carolina Birth Defects Monitoring Program and University of NC Craniofacial Center

Parental Perspectives on Barriers to Care among Children with Orofacial Clefts

Cynthia H. Cassell, Dara Mendez, Ronald P. Strauss, Vanessa White, and Robert Meyer

Background and Objective: Data on perceived barriers to care among families of children with orofacial clefts (OFC) are lacking. Without evaluating qualitative data on families of children with OFC, the extent such barriers exist is unknown. Such problems may include financial and non-financial factors, which can impede receipt of timely services. The study objective was to examine parental perspectives on barriers to care among children with OFC.

Methods: In 2006, a mail or phone survey was administered to all mothers of North Carolina resident children with OFC identified by the North Carolina Birth Defects Monitoring Program born between 2001 and 2004 (n=485). The survey was administered in English and Spanish and included 76 closed and open-ended questions. Thirty-nine questions were taken from a validated, reliable 'barriers to care' questionnaire of parents of children with chronic health conditions. Univariate and bivariate analyses were conducted to determine the most common problems parents encountered accessing primary cleft care for their child within the last 12 months. A p-value of <0.05 was considered statistically significant. Multivariate analysis will be conducted to determine which demographic factors contributed most to barriers to care among this population.

Results: Of 478 eligible participants, 4.4% (n=21) refused to participate, 43.7% (n=209) were lost to follow-up and 52.9% (n=248) individuals responded. When rank-ordered and the non-applicable and missing were omitted (n=59, 24.1%), the most common barriers identified as often or almost always a problem were: taking time off work (23.2%); waiting too long in the waiting room (14.2%); cost of primary cleft care (13.3%); taking care of household responsibilities (13.0%); and meeting the needs of other family members (12.1%). Controlling for cleft type (cleft lip alone, cleft palate alone, and cleft lip with cleft palate), no statistically significant results were found between these barriers and the following selected demographics: maternal race, maternal education, maternal health insurance, child's race, and child's insurance. However, problems meeting the needs of other family members and child's race of American Indian was statistically significant (p-value=0.02). One participant stated, "[I]nsurance and hospitals have not been willing to work with us as far as getting estimates and setting up an agreeable payment plan and forms being filed/processed correctly through insurance" for surgical costs. Another participant explained, "No one ever took into consideration the cost of his care and the debt/income we incurred paying for his care and lost time off work due to being there for surgeries, hospitalizations, and sickness." Despite these problems, 86.6% of participants said within the last 12 months, primary cleft care almost always or often worked well for their child.

Conclusions: Although many barriers were identified, majority of participants were satisfied with primary cleft care for their children. These barriers need to be addressed to increase access to care among children with OFC. Future research is warranted on developing programs and policies to increase access to care among children with birth defects such as OFC.

C4.10 Puerto Rico Birth Defects Surveillance System

Women Reactions to the Puerto Rico Folic Acid Campaign

Diana Valencia and Laureane Alvelo-Maldonado

Objectives: The Puerto Rico Folic Acid Campaign started in 1994. In 2003, based on the recommendations of a marketing study the focus of the campaign was modified. In 2007 we evaluated the new Campaign messages in order to: 1) assess level of awareness and recall of the Puerto Rico folic acid advertising campaign, and 2) explore reactions to the folic acid campaign messages as stated in the 2004 Campaign, and its effect on general attitudes toward folic acid consumption.

Methods: Interviews were conducted by experienced interviewers between February and May 2007. Participant selection was carried out using a stratified random sample selection by geographic area based on the 2000 US Census of population. House to house personal interviews were conducted with non pregnant woman of reproductive age using a structured questionnaire. In addition, during part of the interview the interviewer showed interviewee the Campaign brochure that contains all campaign messages.

Results: A total of 725 women were interviewed. All women were of reproductive age; 13.1% were 15-18 years, 40.8% were 19-35 years, and 46.1% were 36 years or older. At least one person was working full time in 65% of the households interviewed, 44% reported having a family income of less than $15,000, and 42% were receiving government aid at the time of the interview. Most of the women interviewed (58%) were aware of the PR Folic Acid Campaign, although 36% were able to recall the campaign without being prompted by the interviewer. Of those who remembered the campaign spontaneously, 23% knew that folic acid vitamin intake helps to deliver healthier babies, 38% thought it is only for pregnant women, and only 10% thought that everyone should consume it. The interviewees remembered some TV interventions (77%) more frequently than the brochures (37%). The participants found the message of campaign easy to understand (98%), believable (99%), and motivating (89%). Participants found the brochure motivating because it mentions other benefits of the vitamin and not only prevention of neural tube defects.

Conclusions: Over 300,000 people were exposed to the brochure between years 2004-2007; however most people remember the five TV interventions done during the same period. TV interventions appear to have a much greater impact than the brochures. Therefore, increasing the number of TV interventions could be a good strategy to increase awareness of folic acid benefits and therefore its consumption. We need to continue stressing other benefits of the vitamin if we want to increase consumption because: 1) Puerto Rican women do not feel that they are at risk of becoming pregnant, 2) very few people use folic acid if they are not pregnant and 3) still there are people that believe that folic acid is only for pregnant women. With this new campaign more people are aware of other benefits of the vitamin and this has motivated them to take it. We also need to strengthen collaborations with pediatricians in order to increase consumption and create awareness of other vitamin benefits so parents will be more willing to give the vitamin to their children.

C4.11 Utah Birth Defect Network

WIC Vitamin Pilot Project to Enhance Folic Education in Utah, 2000-2003

Amy E. Nance, Marcia L. Feldkamp

Background: The Utah Birth Defect Network is a statewide birth defect surveillance program that has monitored neural tube defects (NTDs) since 1994, for all pregnancy outcomes. UBDN data has demonstrated that women who have had a pregnancy affected by an NTD were more likely to be multiparous and under 30 years of age. The Utah WIC program serves approximately 50% of women and infants and reflects characteristics of women having babies with NTDs: 85% were under 30 years of age and likely have at least one child. Because maternal characteristics of the WIC clients were similar to the population we wished to target, the education and multivitamin project was piloted in the statewide WIC Program.

Objective: A pilot study to assess face-to-face education and intervention with free multivitamins in the WIC population.

Methods: Educational materials and multivitamins were provided for each WIC clinic and were then given, in face-to-face sessions, to nonpregnant women enrolled in WIC, beginning in 2000. Program evaluation was conducted via the WIC Client Satisfaction Survey.

Results: 3,694 women completed the survey (76% English, 24% Spanish) for a response rate of 88%: mean age was 27 years, 71% were 19-33 years of age, 62% white and 36% Hispanic. Of the 3,007 women who answered the question regarding the WIC Vitamin Project, 626 (21%) stated they received the free bottle of multivitamins with 525 (88%) stating they had taken them: 215 (41%) finished the bottle, 59 (11%) finished the bottle and received another, and 231 (44%) consumed part of the bottle.

Conclusions: This pilot project was well received by both clinic staff and the women served. Educating on the importance of consuming folic acid may facilitate the consumption of multivitamins for NTD prevention. A multifactorial study design will be necessary to assess whether face-to-face education with and without free multivitamins facilitates behavior change.