Collaborative Data Projects of the State Data Committee, National Birth Defects Prevention Network

Mark A. Canfield Ph.D.
Manager, Birth Defects Epidemiology and Surveillance Branch, Texas Department of State Health Services and
Co-Chair, State Data Committee, National Birth Defects Prevention Network

Presented for a Special Session at the 14th Annual Meeting of the National Birth Defects Prevention Network
Orlando, Florida, February 27-March 2, 2010
Collaborative Data Projects of the State Data Committee
14th Annual Meeting of the National Birth Defects Prevention Network

Session Topics

Review of NBDPN/Data Committee Publications – Mark Canfield
Descriptive Study of Pyloric Stenosis: New Data – Paul Romitti
Descriptive Study of Ventral Wall Defects: New Data – Russell Kirby
Descriptive Study of Biliary Atresia: New Data – Russel Rickard
“Bundled” Call for Data and Repository Concept for Multiple Projects:
  Race/Ethnicity/Nativity and Birth Defects – Mark Canfield/Russ Kirby
  Survival of Children with Birth Defects – Ying Wang
  Time Trends for Selected Birth Defects – Adolfo Correa
Descriptive Studies of Additional Birth Defects
“Spinoff” Studies and Other Projects
Open Discussion on New Research Project Ideas
State Data Committee  
National Birth Defects Prevention Network

• Oversee collection and presentation of state data annually
• Develop definitions, policies, procedures re: data and statistics used
• Coordinate data use and data sharing
• Providing technical assistance for data
Publications Resulting from Collaborative Data Projects National Birth Defects Prevention Network

(in order of publication, beginning 2002)
Prevalence of Spina Bifida and Anencephaly During the Transition to Mandatory Folic Acid Fortification in the United States

LAURA J. WILLIAMS,1* CARA T. MAI,1 LARRY D. EDMONDS,1 GARY M. SHAW,2 RUSSELL S. KIRBY,3 CHARLOTTE A. HOBBS,4 LOWELL E. SEVER,5 LISA A. MILLER,6 F. JOHN MEANEY,7 AND MIRIAM LEVITT8

1National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, Georgia 30341
2California Birth Defects Monitoring Program, Oakland, California 94606
3Milwaukee Clinical Campus, University of Wisconsin Medical School, Milwaukee, Wisconsin 53201
4Arkansas Reproductive Health Monitoring System, University of Arkansas for Medical Sciences, Little Rock, Arkansas 72211
5University of Texas School of Public Health, Houston, Texas 77030
6Colorado Department of Public Health and Environment, Denver, Colorado 80246
7Department of Pediatrics, Arizona Health Sciences Center, Tucson, Arizona 85724
8Child Policy Research Center, Children’s Hospital Medical Center, University of Cincinnati, Cincinnati, Ohio 45221
Prevalence of Spina Bifida and Anencephaly During the Transition to Mandatory Folic Acid Fortification in the United States

• 5,630 cases of SB and Anencephaly among 24 states participating in “NTD rapid ascertainment”


• After the mandatory fortification date of the U.S. grain supply with folic acid (Jan 1, 1998):
  – Spina Bifida prevalence **decreased by 31%** (p<0.05)
  – Anencephaly prevalence **decreased by 16%** (p<0.05)
    (driven by pgms w/ specialized prenatal asc)

Laura J. Williams, MPH*; Sonja A. Rasmussen, MD*; Alina Flores, MPH*; Russell S. Kirby, PhD‡; and Larry D. Edmonds, MSPH*

• 5,468 SB cases and 2,625 anencephaly cases
• 21 states participating in “NTD rapid ascertainment”

• Spina Bifida prevalence decreased:
  – 34% in Whites
  – 36% in Hispanics
  – 19% in Blacks (not significant)

• Anencephaly prevalence decreased:
  – 29% in Whites
  – 26% in Hispanics
  – 9% in Blacks (not significant)
Changes in the Birth Prevalence of Selected Birth Defects after Grain Fortification with Folic Acid in the United States: Findings from a Multi-State Population-Based Study

Mark A. Canfield, Julianne S. Collins, Lorenzo D. Botto, Laura J. Williams, Cara T. Mai, Russell S. Kirby, Kay Pearson, Owen Devine, and Joe Mulinare, for the National Birth Defects Prevention Network

1 Birth Defects Epidemiology and Surveillance Branch, Texas Department of State Health Services, Austin, TX
2 JC Self Research Institute of Human Genetics, Greenwood Genetic Center, Greenwood, SC
3 National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, GA
4 Department of Maternal and Child Health, School of Public Health, University of Alabama at Birmingham, Birmingham AL
5 Oklahoma State Department of Health, Oklahoma City, OK
Changes in the Birth Prevalence of Selected Birth Defects after Grain Fortification with Folic Acid in the United States: Findings from a Multi-State Population-Based Study

- 16 defects, 23 programs, 1999-2000 v. 1995-96
- Significant reductions in prevalence:
  - Spina Bifida - 34% decrease (confirmed Williams)
  - Anencephaly - 16% decrease (confirmed Williams)
  - Transposition of the Great Arteries - 12% decrease
  - Cleft Palate - 12% decrease
  - Upper Limb Reduction – 11% decrease
  - Pyloric Stenosis - 5% decrease
  - Omphalocele - 21% decrease
Changes in the Birth Prevalence of Selected Birth Defects after Grain Fortification with Folic Acid in the United States: Findings from a Multi-State Population-Based Study

• Substantial *reductions* for certain subgroups:
  – Upper Limb Reduction Defects in Hispanics (44%)
  – Common Truncus in Hispanics (45%)
  – Renal Agenesis – among programs w/ specialized prenatal ascertainment (28%)

• Significant *increases* in prevalence:
  – Down Syndrome (7%)
  – Obstructive Genitourinary Defects (12%)
Survival of Infants With Neural Tube Defects in the Presence of Folic Acid Fortification

Kirk A. Bol, MSPH\textsuperscript{a}, Julianne S. Collins, PhD\textsuperscript{b}, Russell S. Kirby, PhD, MS\textsuperscript{c}, for the National Birth Defects Prevention Network

\textsuperscript{a}Colorado Responds to Children With Special Needs, Colorado Department of Public Health and Environment, Denver, Colorado; \textsuperscript{b}JC Self Research Institute of Human Genetics, Greenwood Genetic Center, Greenwood, South Carolina; \textsuperscript{c}Department of Maternal and Child Health, School of Public Health, University of Alabama at Birmingham, Birmingham, Alabama

The authors have indicated they have no financial relationships relevant to this article to disclose.
Survival of Infants With Neural Tube Defects in the Presence of Folic Acid Fortification

• Retrospective cohort study of 2,841 infants with spina bifida and 638 infants with encephalocele
• 16 participating birth defects monitoring programs
• Improved 1-year survival for infants w/ spina bifida
  – 90% survival before Folic Acid Fortification
  – 92% survival after Folic Acid Fortification


1Birth Defects Epidemiology and Surveillance Branch, Texas Department of State Health Services, Austin, Texas
2National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, Georgia
3March of Dimes Birth Defects Foundation, White Plains, New York
4JC Self Research Institute of Human Genetics, Greenwood Genetic Center, Greenwood, South Carolina
5Arkansas Center for Birth Defects Research and Prevention, Little Rock, Arkansas
6Department of Maternal and Child Health, School of Public Health, University of Alabama, Birmingham, Alabama

Received 7 April 2006; Revised 17 July 2006; Accepted 17 July 2006
Established national prevalence estimates for 21 “clinically accurate” birth defects using pooled data.

22 state programs:
- 11 active case ascertainment (22% of all live births)
- 4 passive with case confirmation
- 7 passive w/o case confirmation

Active surveillance programs tended to record higher prevalences
Among 11 active surveillance programs, of the defects studied:

- Highest adjusted prevalences observed for Down syndrome and orofacial clefts
- Hispanics had higher crude prevalence than whites for Spina Bifida, Anencephaly, Encephalocele, Gastrochisis, DS
- Blacks had higher crude prevalence than whites for Tetralogy of Fallot, lower limb reduction defect, Trisomy 18
- Hispanics had lower crude prevalence than whites for Tetralogy of Fallot, HLHS, CP, Esophageal atresia
- Blacks had lower crude prevalence than whites for HLHS, CP, Esoph atresia, Gastrochisis, DS
Birth Defects Interstate Data Exchange: A Battle Worth Fighting?

Cynthia Cassell,¹* Cara Mai,² and Russel Rickard³

¹North Carolina Birth Defects Monitoring Program, State Center for Health Statistics, Division of Public Health, Raleigh, North Carolina
²National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, Georgia
³Colorado Responds to Children with Special Needs, Colorado Department of Public Health and Environment, Denver, Colorado

Received 13 August 2007; Revised 6 September 2007; Accepted 6 September 2007
Birth Defects Interstate Data Exchange: A Battle Worth Fighting?

• Assessed the range and impact of out-of-state births
• According to NCHS:
  – 4 states (NH, VT, WV, ME) had >10% of resident births occurring out of state
  – 4 states (HI, CA, FL, TX) had <0.5% out of state births
• 7 states (of 34 that responded to a survey) had interstate data exchange agreements for birth defects surveillance
Trends in the Postfortification Prevalence of Spina Bifida and Anencephaly in the United States

Sheree L. Boulet, Quanhe Yang, Cara Mai, Russell S. Kirby, Julianne S. Collins, James M. Robbins, Robert Meyer, Mark A. Canfield, Joe Mulinare, for the National Birth Defects Prevention Network

1National Center on Birth Defects and Developmental Disabilities, CDC, Atlanta, Georgia
2Department of Maternal and Child Health, School of Public Health, University of Alabama at Birmingham, Birmingham, Alabama
3C Self Research Institute of Human Genetics, Greenwood Genetic Center, Greenwood, South Carolina
4Department of Pediatrics, University of Arkansas for Medical Sciences, Little Rock, Arkansas
5North Carolina Center for Health Statistics, Raleigh, North Carolina
6Birth Defects Epidemiology and Surveillance Branch, Texas Department of State Health Services, Austin, Texas

Received 31 January 2008; Revised 11 March 2008; Accepted 11 March 2008
Trends in the Postfortification Prevalence of Spina Bifida and Anencephaly in the United States

- 3,311 spina bifida and 2,116 anencephaly cases
- Hispanics had the highest prevalence for SB, An in all years
- Continued to see significant declines in anencephaly prevalence *after fortification was in place*, but only among whites
The Association Between Major Birth Defects and Preterm Birth

Margaret A. Honein · Russell S. Kirby · Robert E. Meyer · Jian Xing · Nyasha I. Skerrette · Nataliya Yuskiv · Lisa Marengo · Joann R. Petrini · Michael J. Davidoff · Cara T. Mai · Charlotte M. Druschel · Samara Viner-Brown · Lowell E. Sever · for the National Birth Defects Prevention Network

© Springer Science+Business Media, LLC 2008
The Association Between Specific Types of Major Birth Defects and Preterm Birth

- 230,000 infants w/ defects among 7 M births and 30 programs (30% of all U.S. births), 1995-2000

- Overall, 8% of preterm infants had a birth defect, and 16% of very preterm infants had a birth defect.

- Birth defects were ~ 2.6 times more common among preterm infants (32-36 weeks).

- Birth defects were 5 times more common among very preterm infants (24-31 weeks).

- Largest association seen with CNS and cardiovascular defects
Multistate Study of the Epidemiology of Clubfoot


1National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, Georgia
2Rollins School of Public Health, Emory University, Atlanta, Georgia
3Colorado Department of Public Health and Environment, Denver, Colorado
4Texas Department of State Health Services, Austin, Texas
5New York State Department of Health, Troy, New York
6North Carolina Center for Health Statistics, Raleigh, North Carolina

Received 30 April 2009; Revised 14 July 2009; Accepted 21 July 2009
Multistate Study of the Epidemiology of Clubfoot

• Determined prevalence and assessed risk factors (case-control study: 10 controls per case)
• 6,139 cases among 10 programs, 2001-2005
• Prevalence - 1.29 per 1,000 live births. Common!
  – Prevalence in whites, Hispanics > blacks
  – Prevalence in CO, TN, IA > NY, PR, NC, Atl, WV
• Risk Factors: male sex, white race/ethnicity*, single or older mom, single, diabetes (pregestational, gestational), smoking*, low gravidity/parity*, plurality, low education level*, Medicaid, prematurity
Public Health Projects for Preventing the
Recurrence of Neural Tube Defects
in the United States

Julianne S. Collins,¹* Mark A. Canfield,² Kay Pearson,³ Russell S. Kirby,⁴
Amy P. Case,² Cara T. Mai,⁵ Judy Major,⁶ and Joe Mulinare,⁵ for the National Birth
Defects Prevention Network

¹J C Self Research Institute of Human Genetics, Greenwood Genetic Center, Greenwood, South Carolina
²Birth Defects Epidemiology and Surveillance Branch, Texas Department of State Health Services, Austin, Texas
³Oklahoma Birth Defects Registry, Oklahoma State Department of Health, Oklahoma City, Oklahoma
⁴Department of Community and Family Health, College of Public Health, University of South Florida, Tampa, Florida
⁵National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, Georgia
⁶North Carolina Birth Defect Monitoring Program, Fullerton Genetics at Mission Hospitals, Asheville, North Carolina

Received 13 May 2009; Revised 17 June 2009; Accepted 18 June 2009
Public Health Projects for Preventing the Recurrence of Neural Tube Defects in the United States

- Survey conducted with State health departments in 2005 to gather information on state activities related to preventing the recurrence of NTDs (An/SB +/- Enceph)
- 13 active (current) prevention projects and 3 planned projects out of 34 states responding
- Only 4 projects actually provided folic acid
- Some reasons for not having this activity: Staffing limitations, lack of funds, low priority, confidentiality
- Key pgm components: Timely case ascertainment, development/dissemination of educational materials
Geocoding Capacity of Birth Defects Surveillance Programs: Results from the National Birth Defects Prevention Network Geocoding Survey

Ying Wang, PhD, MPH; Leslie A. O’Leary, PhD; Russel S. Rickard, MS; Craig A. Mason, PhD for the National Birth Defects Prevention Network
Geocoding of Birth Defects Surveillance Programs: Results from the National Birth Defects Prevention Network Geocoding Survey

• Web-based survey of state programs, 2007
• Completed by 39 of 53 state birth defects program contacts
• Approx. 50% of reporting states geocoded delivery addresses
• Barriers for remaining respondents included lack of software or funding issues

Samantha E. Parker,¹,² Cara T. Mai,¹* Mark A. Canfield,³ Russel Rickard,⁴ Ying Wang,⁵ Robert E. Meyer,⁶ Patrick Anderson,⁷ Craig A. Mason,⁸ Julianne S. Collins,⁹ Russell S. Kirby,¹⁰ and Adolfo Correa¹ for the National Birth Defects Prevention Network

¹National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, Georgia
²Oak Ridge Institute of Science and Education, Oak Ridge, Tennessee
³Birth Defects Epidemiology and Surveillance Branch, Texas Department of State Health Services, Austin, Texas
⁴Colorado Department of Public Health and Environment, Denver, Colorado
⁵New York State Department of Health, Troy, New York
⁶North Carolina Birth Defects Monitoring Program, State Center for Health Statistics, Raleigh, North Carolina
⁷California Department of Public Health, Sacramento, California
⁸University of Maine, Orono, Maine
⁹J.C. Self Research Institute of Human Genetics, Greenwood Genetic Center, Greenwood, South Carolina
¹⁰University of South Florida, Tampa, Florida

Received 1 June 2010; Revised 9 July 2010; Accepted 29 July 2010

• Updated earlier prevalence estimates (1999-2001)-21 defects and 24 programs:
  – 11 active case ascertainment
  – 6 passive with case confirmation
  – 7 passive without case confirmation

• Active programs showed a higher prevalence for anencephaly (An), eye defects, CL w/ or w/o CP, upper limb reduction defects, Trisomy 18

• Programs including elective terminations: higher prevalence of An, Trisomy 13 & 18
Prevalence at Birth of Cleft Lip With or Without Cleft Palate: Data From the International Perinatal Database of Typical Oral Clefts (IPDTOC)

IPDTOC Working Group

Cleft Palate–Craniofacial Journal, January 2011, Vol. 48 No. 1
Submitted November 2009; Accepted April 2010
Prevalence at Birth of Cleft Lip with or without Cleft Palate: Data from the International Perinatal Database of Typical Oral Clefts (IPDTOC)

- International collaborative data project with WHO; contributors: NBDPN, International Clearinghouse, Eurocat; 2000-2005
- 54 registries, 30 countries. Case by case review
- 7,704 cases among 7.5 million live births
- Prev of CL=3.28, Prev of CL+CP=6.64 (per 10,000)
- Reporting site with highest total prevalence: Japan
- 77% isolated, 16% multiples, 7% syndromic
- Increased cleft severity with multiple anomalies
- Also examined laterality
Other Projects in Progress or Under Consideration

- Descriptive studies on selected birth defects
  - Abdominal wall defects
  - Pyloric stenosis
  - Biliary atresia
- Race/Ethnicity/Nativity and selected birth defects
- Time trend analysis for selected birth defects
- Mortality/Survival
- Air pollution (ozone, particulates) and clefts
- Urban vs. rural prevalence/patterns
- Infant sex ratios/differences
- Descriptive Studies on >20 birth defects
- Other
Birth Defects included in Recent Call for Data for Race/Ethnicity/Nativity and “Spinoff” Projects

- **NTDs/CNS:** Anencephaly, Spina bifida (w/o anencephaly), Encephalocele
- **Ear Defects:** Anotia/microtia
- **Heart Defects:** Common truncus, Transposition, Tetralogy of fallot, Endocardial cushion defect (w/o Down syndrome), Hyopoplastic left heart syndrome, Coarctation of the aorta, Aortic stenosis
- **Orofacial clefts:** Cleft lip +/- cleft palate, cleft palate
- **Gastrointestinal:** Esophageal atresia, Rectal/Intestinal atresia/stenosis
- **Hypospadias**
- **Limb reduction defects:** Upper, lower
- **Ventral Wall defects:** Gastroschisis, Omphalocele
- **Pyloric stenosis**
- **Diaphragmatic hernia**
- **Chromosomal:** Down Syndrome, Trisomy 13, Trisomy 18
Ideas and Discussion about New NBDPN Research Projects
Thank You!

Other Questions or Comments?

If you have questions or comments after the meeting, please contact Mark Canfield at mark.canfield@dshs.state.tx.us or russel.rickard@state.co.us