

# Iowa Registry for Congenital and Inherited Disorders

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# Surveillance



**Iowa Registry  
for Congenital  
and Inherited  
Disorders**





# IRCID

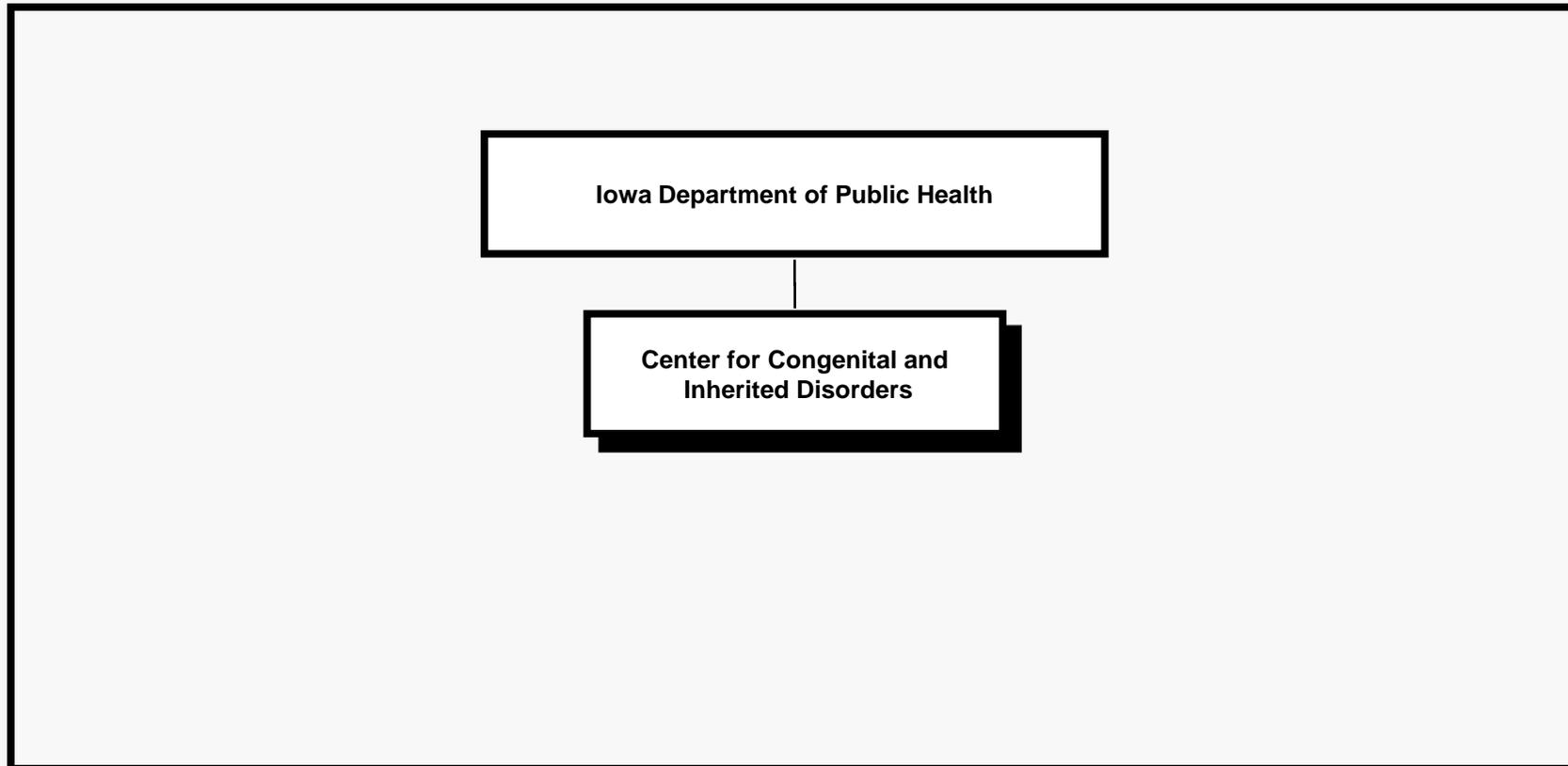
- Established in 1983 as Iowa Birth Defects Registry by:  
Iowa Department of Human Services  
Iowa Department of Public Health (IDPH)  
The University of Iowa (UI)
- Instituted surveillance by change in state code that made birth defects reportable conditions in Iowa
- Program of IDPH chartered to UI College of Public Health



# Legislation – Chapter 136A

- 136A.1 PURPOSE
- *.... initiate, conduct, and supervise screening and health care programs in order to detect and predict congenital or inherited disorders*

# Center for Congenital and Inherited Disorders



# Legislation – Chapter 136A

- 136A.2 DEFINITIONS
- *"Congenital disorder" means an abnormality existing prior to or at birth, including a stillbirth, that adversely affects the health and development of a fetus, newborn, child, or adult, including a structural malformation or a genetic, chromosomal, inherited, or biochemical disorder.*

# Birth Defect

- A major birth defect is an abnormality of **organ structure** or **function**, including metabolism, present at birth that results in physical disability, mental disability, or death
- A minor birth defect is an abnormality that results in medically insignificant departure from normal development

# Legislation – Chapter 136A

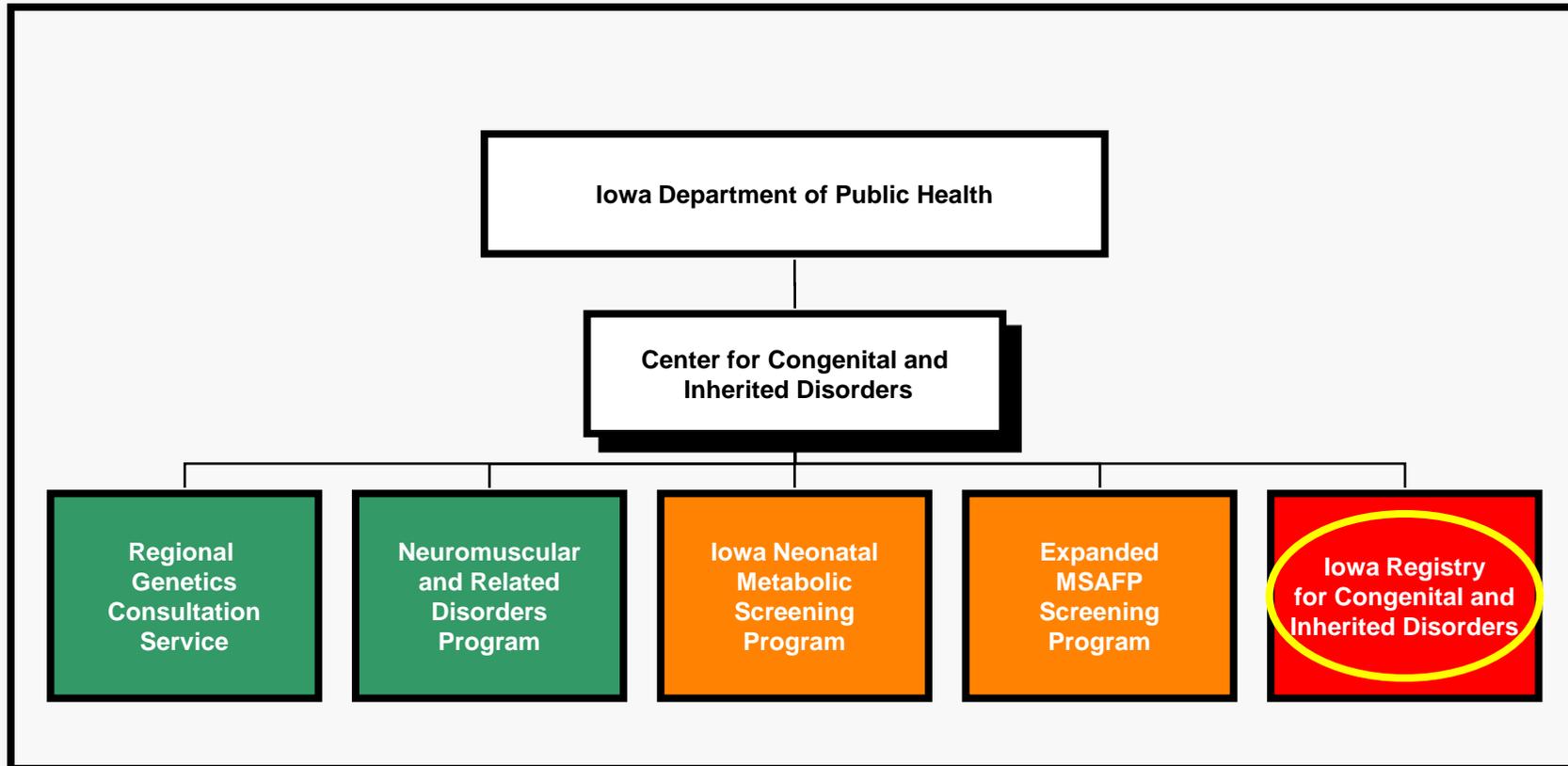
- 136A.3 ESTABLISHMENT OF CENTER FOR CONGENITAL AND INHERITED DISORDERS -- DUTIES
- *Perform **surveillance and monitoring of congenital and inherited disorders** to determine the occurrence and trends of the disorders, to conduct thorough and complete epidemiological surveys, to assist in the planning for and provision of services to children with congenital and inherited disorders and their families, and to identify environmental and genetic risk factors for congenital and inherited disorders.*

# Legislation – Chapter 136A

- 136A.6 CENTRAL REGISTRY
- *The center for congenital and inherited disorders shall maintain a central registry, or shall establish an agreement with a designated contractor to maintain a central registry, to compile, evaluate, retain, and disseminate information on the occurrence, prevalence, causes, treatment, and prevention of congenital disorders. Congenital disorders shall be considered reportable conditions in accordance with rules adopted by the department and shall be abstracted and maintained by the registry.*



# IRCID



# Regulations – Chapter 4 IAC

- 4.7(3) *IRCID activities*
- a. The center shall establish an [agreement with the University of Iowa](#) to implement the activities of the IRCID.
- b. The IRCID shall use birth defects, neuromuscular disorders, metabolic disorders, and stillbirth [coding schemes](#) developed by the Centers for Disease Control and Prevention (CDC).

# Regulations – Chapter 4 IAC

- 641—4.7(136A) Iowa registry for congenital and inherited disorders (IRCID)
- This program provides active statewide surveillance for .... **birth defects, neuromuscular disorders, metabolic disorders, and all stillbirths**. The program also may conduct active statewide surveillance of live births without a reportable congenital or inherited disorder to serve as **controls** for epidemiological surveys. Surveillance activities for specific congenital and inherited disorders will be conducted for the period of time that **adequate financial support** is available.



# Regulations – Chapter 4 IAC

- 4.7(3) *IRCID activities*
- c. The IRCID staff shall review hospital records, clinical charts, physician's records, vital records, prenatal records, and fetal death evaluation protocols pursuant to 641—1.3(139A), information from the INMSP, RGCS, NMP, and the IMPSP, and any other information that the IRCID deems necessary and appropriate for congenital and inherited disorders surveillance.

# Surveillance Mission



Identify



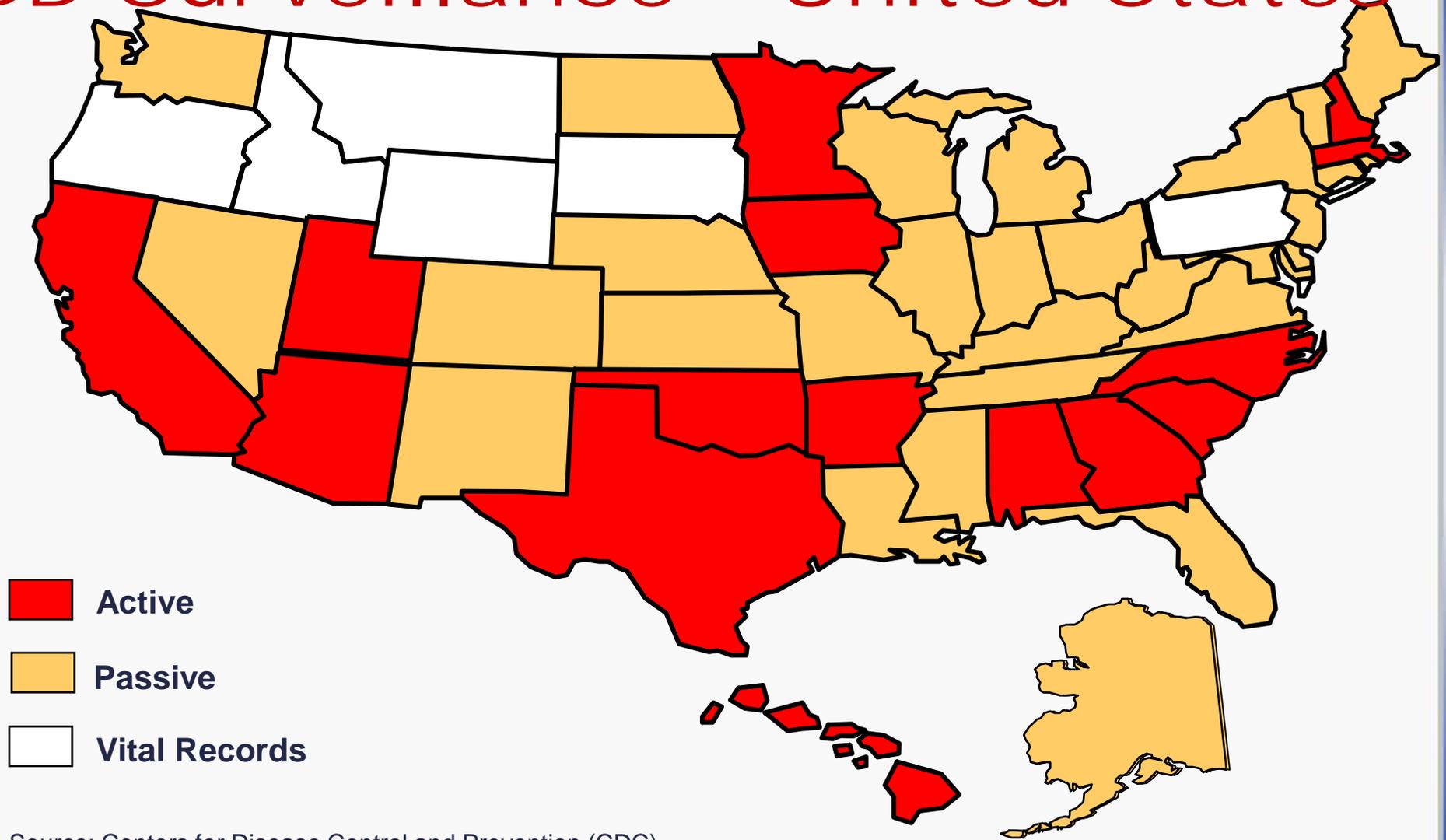
Classify



# Birth Defect Surveillance

- Vital Records (Poor)
  - Use of birth and fetal death certificates provided by state department of health
- Passive Surveillance (Fair-Good)
  - Use of medical reports submitted by staff from hospitals, clinics, or other facilities
- Active Surveillance (Best)
  - Use of trained personnel who systematically review records in hospitals, clinics, and other facilities

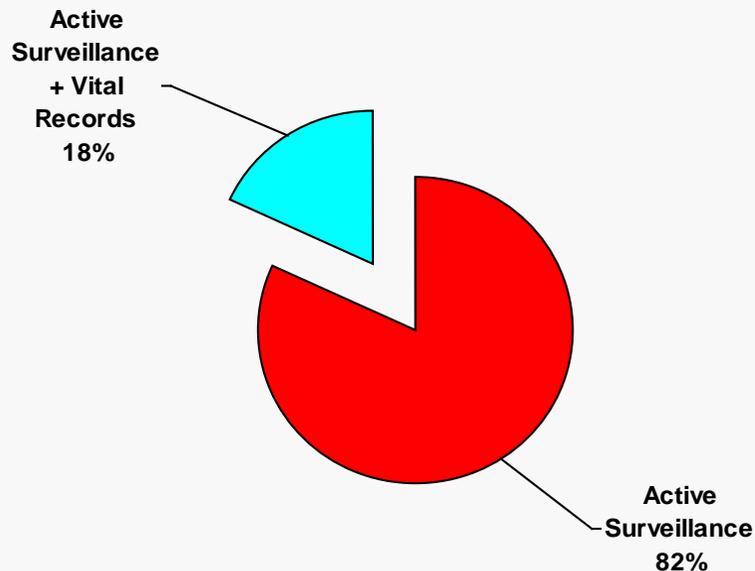
# BD Surveillance - United States



Source: Centers for Disease Control and Prevention (CDC)

# Iowa Birth Defects Ascertainment

## Birth Defect Reports 1998-2002

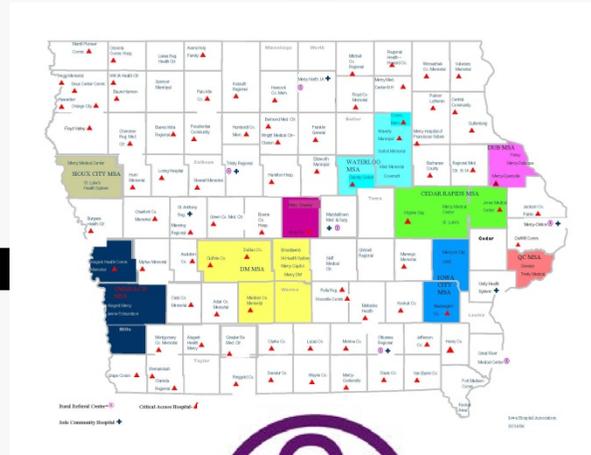


- A record review of 9,080 infants identified by the Registry's active surveillance system showed that vital records would have identified only 1,644 or 18% of these infants. Therefore, for these years, if the Registry relied on vital records only for birth defect surveillance, on average, four out of every five infants diagnosed with a birth defect would not have been identified.



# *Education*

Promote and evaluate education activities for the prevention of birth defects



# *Research*

Conduct research to identify genetic and environmental risk factors for birth defects



# *Outreach*

Provide outreach to appropriate clinical, educational and social services

# Iowa Descriptive Study

RESEARCH ARTICLE

AMERICAN JOURNAL OF  
medical genetics **A** PART

## Epidemiology of Congenital Idiopathic Talipes Equinovarus in Iowa, 1997–2005

Vijaya Kancherla,<sup>1</sup> Paul A. Romitti,<sup>1\*</sup> Kristin M. Caspers,<sup>1</sup> Soman Puzhankara,<sup>1</sup> and Jose A. Morcuende<sup>2</sup>

<sup>1</sup>Department of Epidemiology, College of Public Health, The University of Iowa, Iowa City, Iowa

<sup>2</sup>Department of Orthopedic Surgery, Carver College of Medicine, The University of Iowa, Iowa City, Iowa

# In-Vitro Fertilization

## **In vitro fertilization is associated with an increase in major birth defects**

*Christine K. Olson, M.D., M.P.H.,<sup>a</sup> Kim M. Keppler-Noreuil, M.D.,<sup>b</sup> Paul A. Romitti, Ph.D.,<sup>c</sup> William T. Budelier,<sup>c</sup> Ginny Ryan, M.D.,<sup>a</sup> Amy E. T. Sparks, Ph.D.,<sup>a</sup> and Bradley J. Van Voorhis, M.D.<sup>a</sup>*

<sup>a</sup>Division of Reproductive Endocrinology and Infertility, Department of Obstetrics and Gynecology, University of Iowa;

<sup>b</sup>Iowa State Birth Defects Registry; and <sup>c</sup>College of Public Health, University of Iowa, Iowa City, Iowa

# Multistate Multiregistry Study



OPEN ACCESS Freely available online



## Cancer Risk in Children and Adolescents with Birth Defects: A Population-Based Cohort Study

Lorenzo D. Botto<sup>1\*</sup>, Timothy Flood<sup>2</sup>, Julian Little<sup>3</sup>, Mark N. Fluchel<sup>4</sup>, Sergey Krikov<sup>1</sup>, Marcia L. Feldkamp<sup>1</sup>, Yuan Wu<sup>5</sup>, Rhinda Goedken<sup>5</sup>, Soman Puzhankara<sup>5</sup>, Paul A. Romitti<sup>5</sup>

# Multistate Research Studies



national • birth • defects • prevention • study

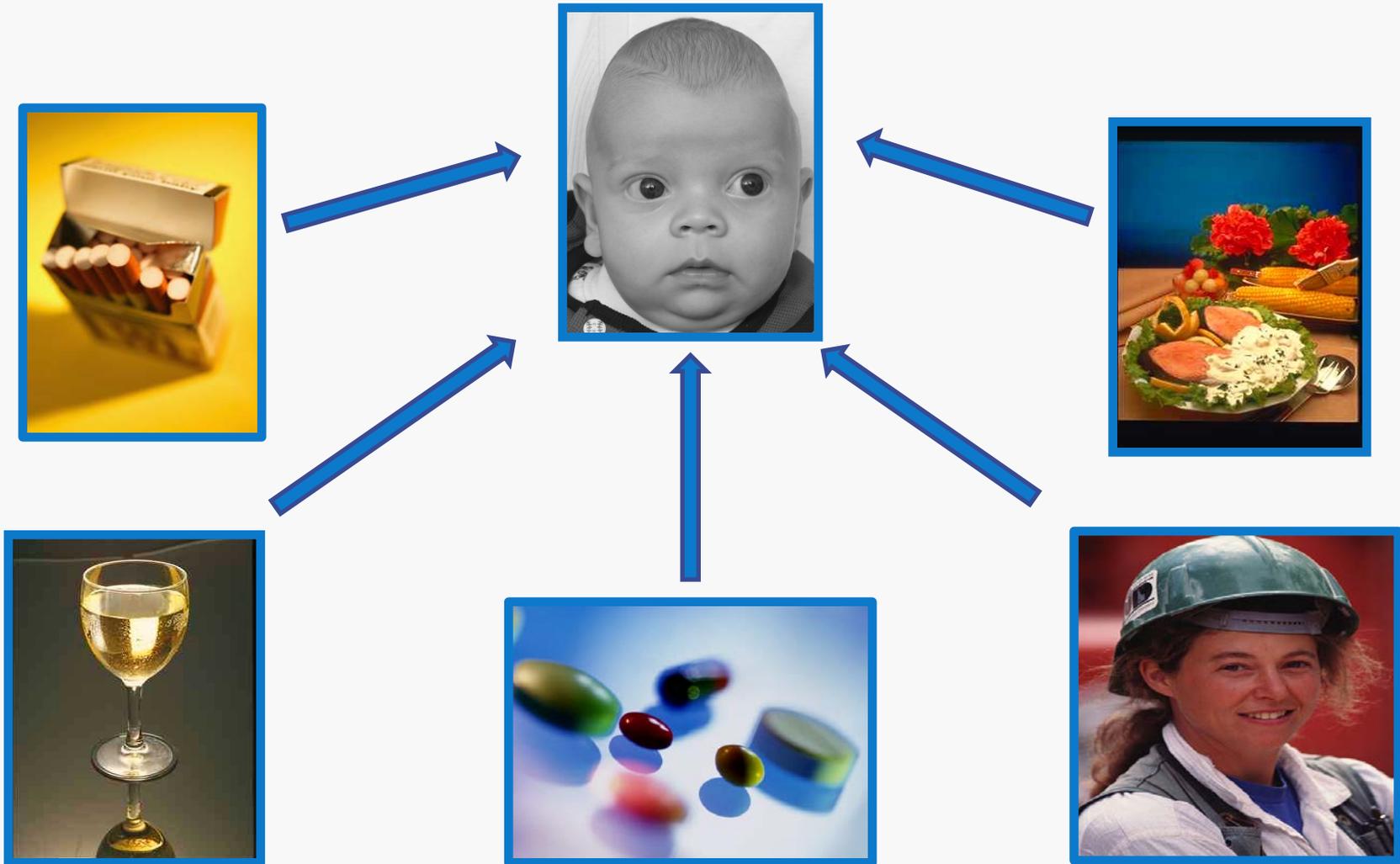


National  
Down Syndrome  
Project



Centers for Birth Defects Research and Prevention

# Maternal Exposures



# Medications



**ANTI-FUNGALS**





national • birth • defects • prevention • study

nature  
genetics

## A genome-wide association study identifies susceptibility loci for nonsyndromic sagittal craniosynostosis near *BMP2* and within *BBS9*

Cristina M Justice<sup>1,24</sup>, Garima Yagnik<sup>2,24</sup>, Yoonhee Kim<sup>1</sup>, Inga Peter<sup>3</sup>, Ethylin Wang Jabs<sup>3</sup>, Monica Erazo<sup>3</sup>, Xiaoqian Ye<sup>3</sup>, Edmond Ainehsazan<sup>3</sup>, Lisong Shi<sup>3</sup>, Michael L Cunningham<sup>4</sup>, Virginia Kimonis<sup>5</sup>, Tony Roscioli<sup>6</sup>, Steven A Wall<sup>7</sup>, Andrew O M Wilkie<sup>7,8</sup>, Joan Stoler<sup>9</sup>, Joan T Richtsmeier<sup>10</sup>, Yann Heuzé<sup>10</sup>, Pedro A Sanchez-Lara<sup>11</sup>, Michael F Buckley<sup>12</sup>, Charlotte M Druschel<sup>13</sup>, James L Mills<sup>14</sup>, Michele Caggana<sup>15</sup>, Paul A Romitti<sup>16</sup>, Denise M Kay<sup>15</sup>, Craig Senders<sup>17</sup>, Peter J Taub<sup>18</sup>, Ophir D Klein<sup>19-21</sup>, James Boggan<sup>22</sup>, Marike Zwienenberg-Lee<sup>22</sup>, Cyrill Naydenov<sup>23</sup>, Jinoh Kim<sup>2</sup>, Alexander F Wilson<sup>1</sup> & Simeon A Boyadjiev<sup>2</sup>



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Birth Defects Research (Part A) 88:560–569 (2010)

## Caffeine, Selected Metabolic Gene Variants, and Risk for Neural Tube Defects

**Rebecca J. Schmidt,<sup>1,2\*</sup> Paul A. Romitti,<sup>2</sup> Trudy L. Burns,<sup>2</sup> Jeffrey C. Murray,<sup>2,3</sup> Marilyn L. Browne,<sup>4</sup>  
Charlotte M. Druschel,<sup>4</sup> Richard S. Olney<sup>5</sup> and the National Birth Defects Prevention Study**

<sup>1</sup>Department of Public Health Sciences, University of California, Davis, California

<sup>2</sup>Department of Epidemiology, University of Iowa, Iowa City, Iowa

<sup>3</sup>Departments of Pediatrics and Biology, University of Iowa, Iowa City, Iowa

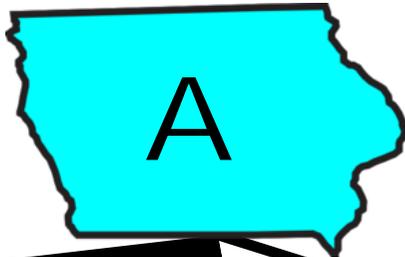
<sup>4</sup>Congenital Malformations Registry, New York State Department of Health, Troy, New York

<sup>5</sup>National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, Georgia

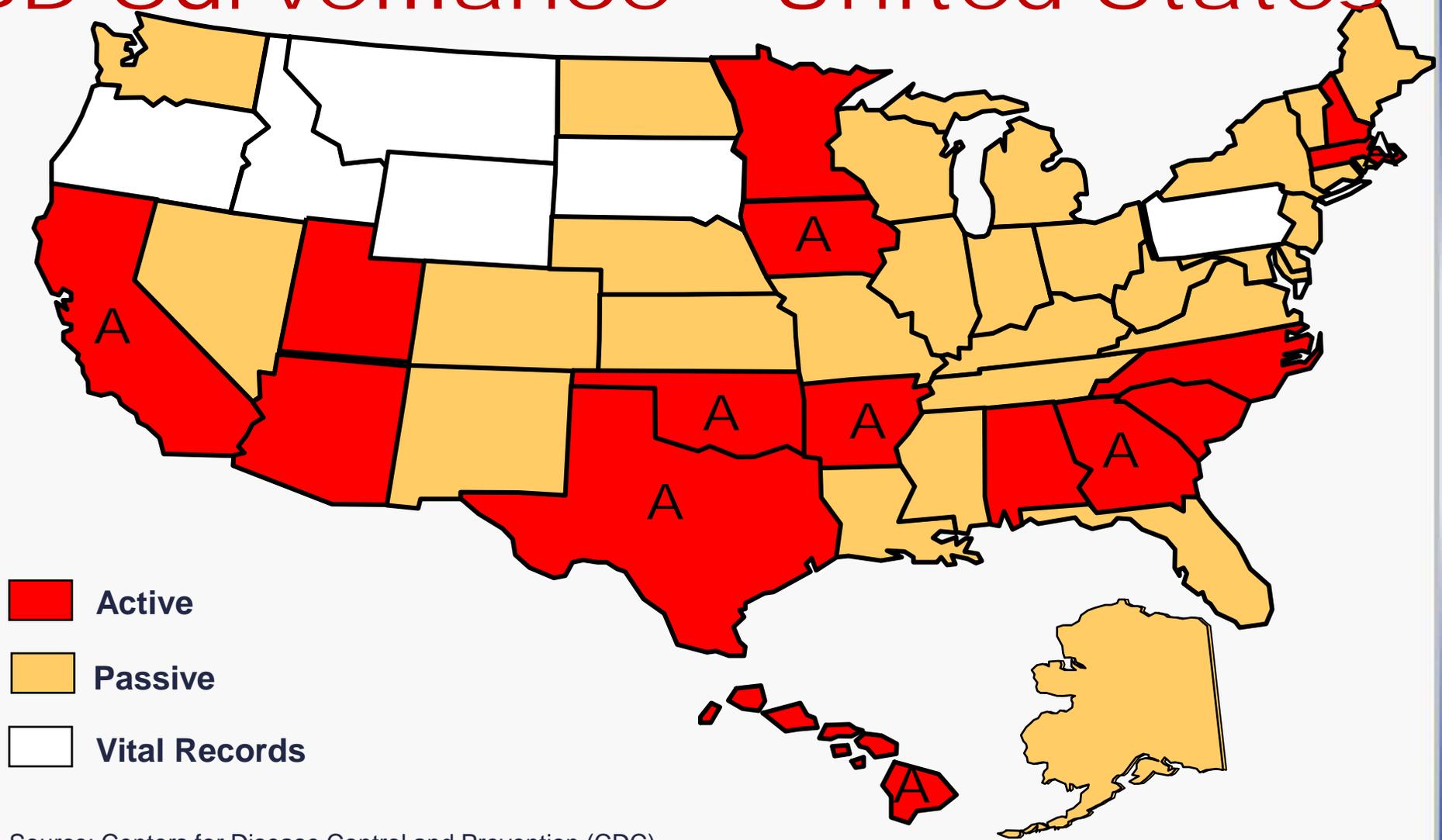
# Awards



- Assigned letter grade to birth defect programs
- Grade reflected program's ability to conduct surveillance, research, and prevention activities

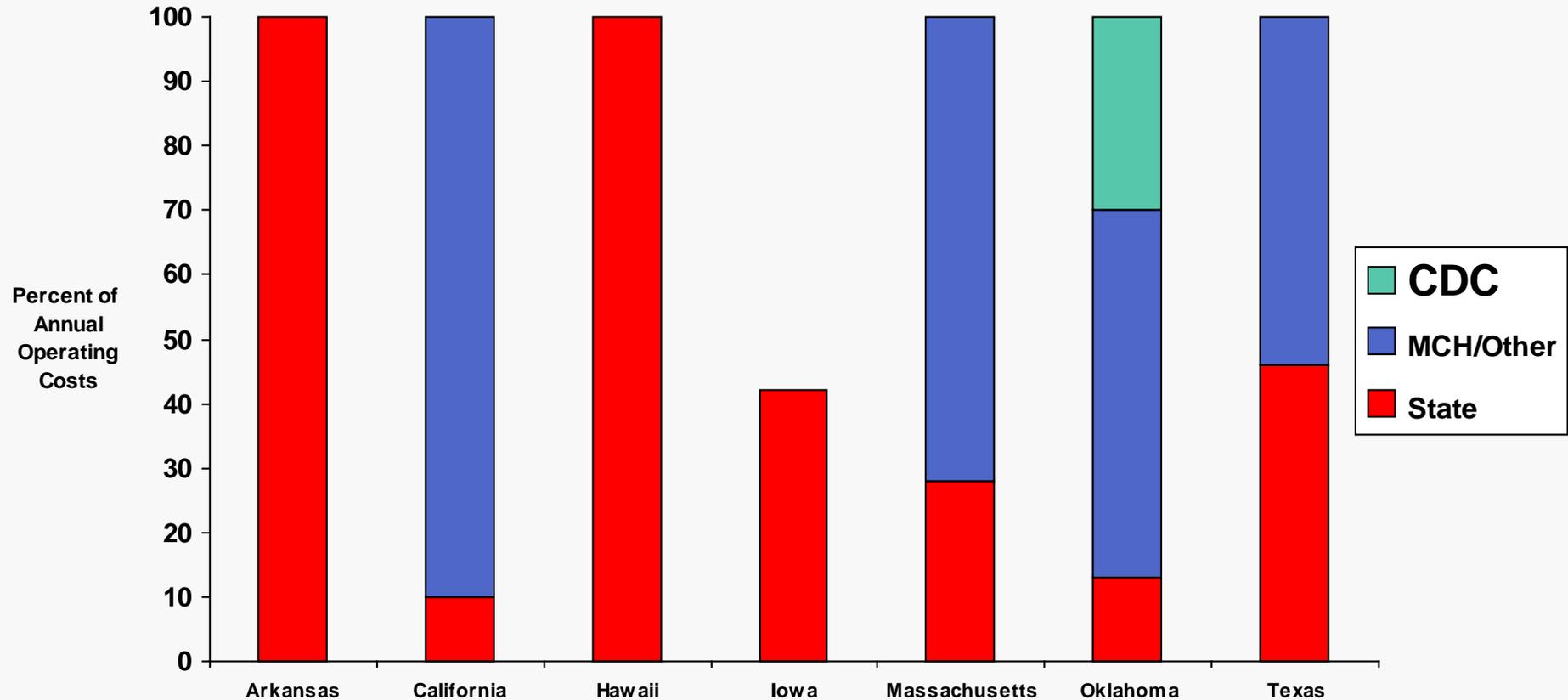


# BD Surveillance - United States



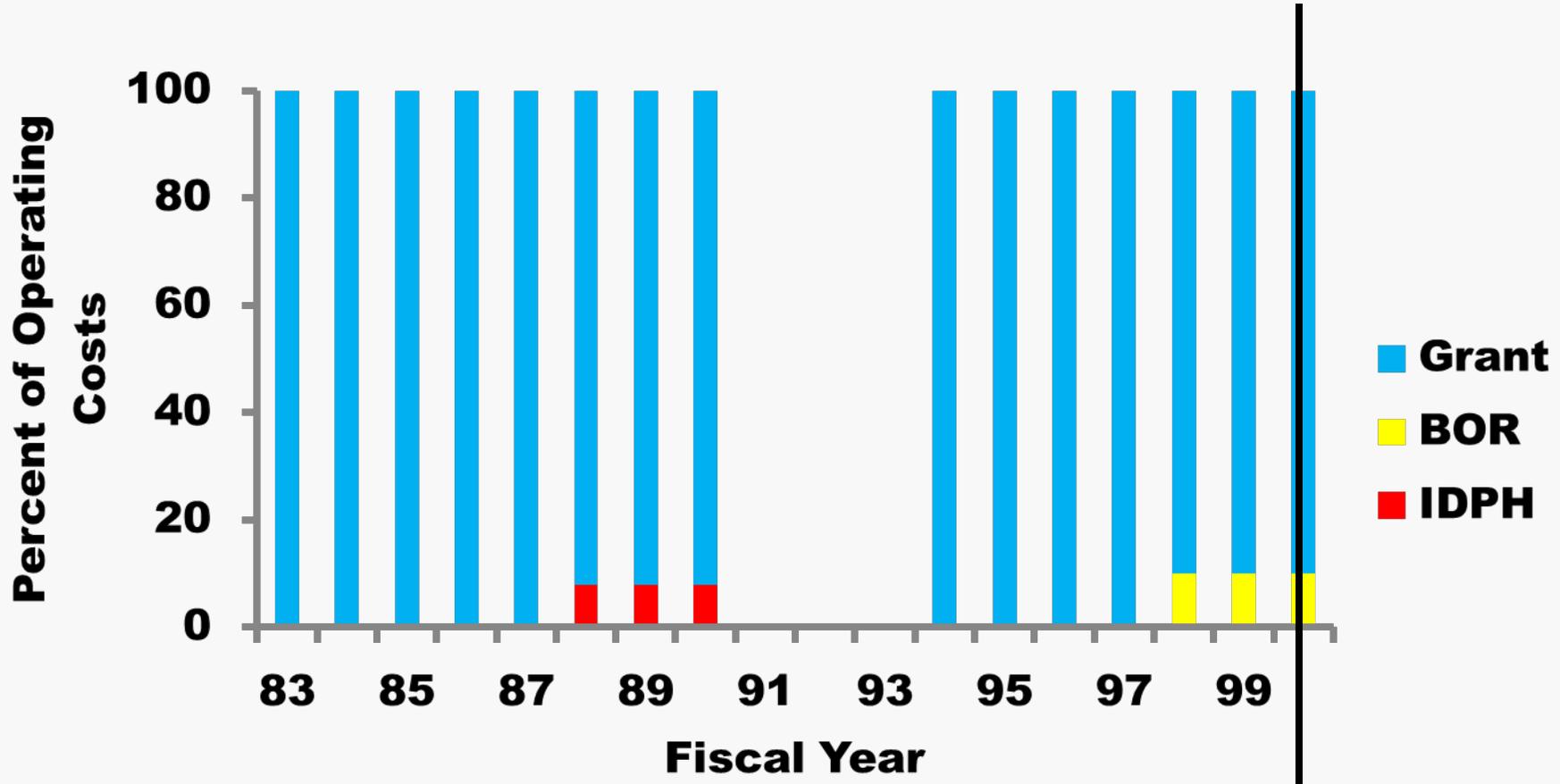
Source: Centers for Disease Control and Prevention (CDC)

# Funding for "A" Registries

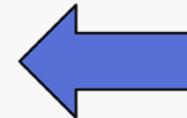
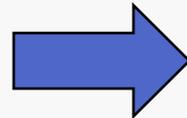


Note: Georgia (CDC) receives 100% federal funding

# Funding Timeline FY1983-2000



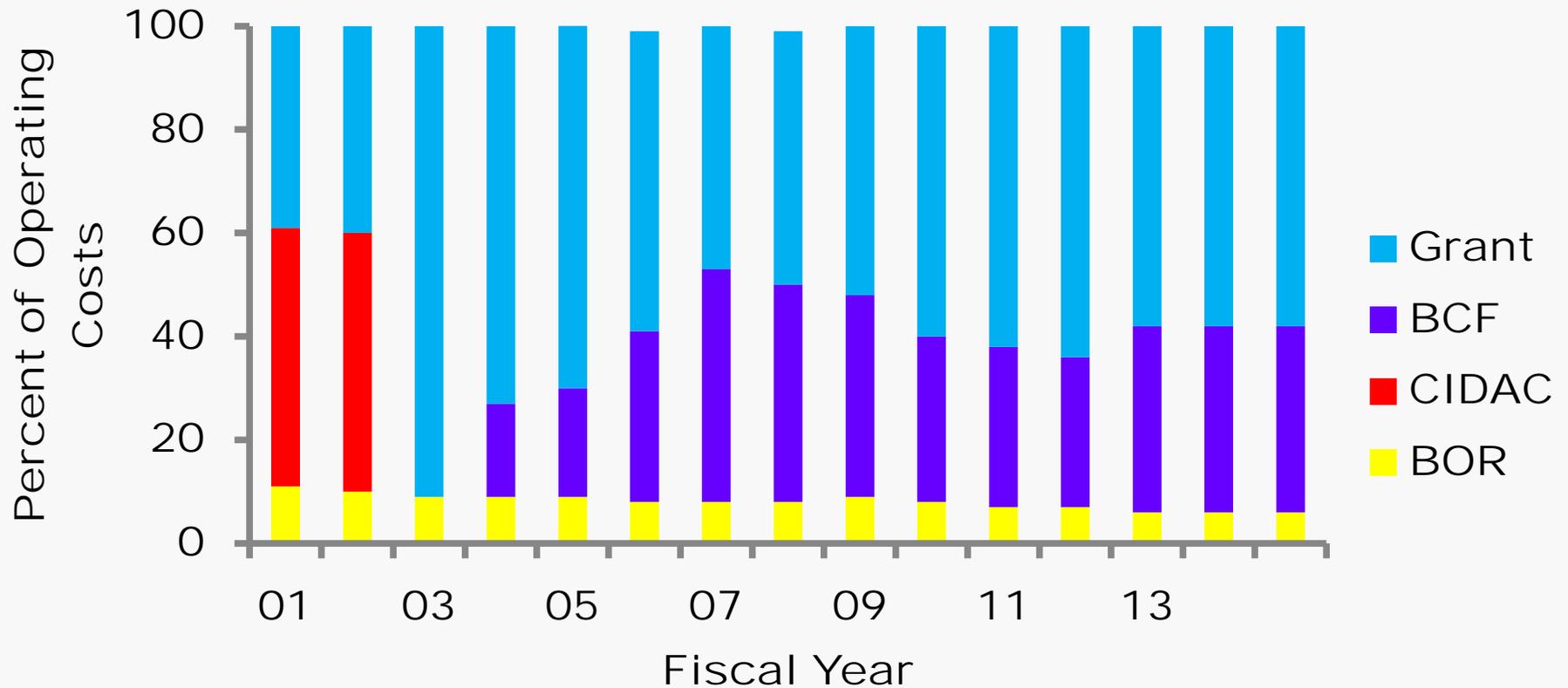
# Coalition-Building



# Birth Certificate Fee Increase

- Four-year effort headed by MOD with assistance from IDPH and UI
- Obtain increased and sustained funding for Registry
- In 2003 and 2004, legislation passed and revised to add fee increase on birth certificates

# Funding Timeline FY2001-2015



# Revenue vs. Grant Funding FY2003-2015

