Environmental Public Health Tracking
Birth Defects on the NYS Portals

NBDPN 15th Annual Meeting
Arlington, Virginia
Feb 27 – Feb 29, 2012

Philip Cross
NYS DOH Center for Environmental Health
NYS Environmental Public Health Tracking

- NYS EPHT Program Overview
- Three Tiered System
  - Local Area Network (LAN)
  - Public Portal
  - Secure Portal
- Birth Defects Query and Displays
New York State’s Environmental Public Health Tracking Program

CDC Grant 2006-2011 to implement a statewide EPHT Network as part of a National EPHT Network. Renewed for 2011-2014.
NYS EPHT Network

• We recognized early in the development of the Network that users will have different levels of expertise and needs for EPHT.

• The NYS EPHT system consists of three tiers.

• Each tier was designed to serve different user needs with multiple levels of access and security.
### NYS EPHT Three Tiered System: General Approach

<table>
<thead>
<tr>
<th>Tier</th>
<th>Features</th>
<th>Access</th>
<th>Purpose</th>
</tr>
</thead>
</table>
| Tier 1 | • Individual level data  
• Statistical tools  
• Mapping tools | Researchers and project staff in Center for Environmental Health (CEH) | Research and Surveillance |
| Tier 2 | • Finer geographic resolution at sub-county level  
• Data query tools  
• Query based data displays including map and charts | Role based access to DOH and County Health professionals  
Access determined by program areas/data owners | Surveillance |
| Tier 3 | • County level data and display  
• Simple data queries, maps, charts, and tables  
• Public health message | Open access  
| | | Outreach | |
NYS EPHT Tier 1
Enables Complex Queries

Graph/Plot Environmental and Health data (Beta 1.02)

- Enter Title for Layout
- Select either Daily or Monthly
- Select pollutant
- Select Start date
- Select Geographical unit for Health Graphs
- Select type of graph
- Select symbol
- Select health outcome
- Select End Date
- Select yes for both, health and air data, on one graph
- Select either counts or rates

Graph Period:
- Daily
- Monthly

Graph Type:
- Line Chart
- Vertical Bar
- Horizontal Bar

Show DEC Monitors As:

Show Grid Cell Graphs For:
- Ozone 8Hours Maximum
- Ozone 1Hour
- PM 2.5
- VarName4

Include Health Data for:
- Asthma (Under 18 years age)
- Cardiovascular Disease
- Low Birth Weight
- CVD Mortality

Start Date for Graph:
05/01/2001

End Date for Graph:
10/31/2001

Select Additional Criteria for Health Outcome Graphs

Health Graphs for:
- Grid
- County
- ZipCode
- Grid and County
- Grid and ZipCode

Right Vertical Axis?
- Yes
- No

Show Health Graph of:
- Counts
- Rate
Examples of NYS EPHT Tier 1 Datasets

**Environmental**
- Air pollution data
- Toxic Release Inventory
- Hazardous Waste Sites
- Traffic Count

**Sociodemographic**
- Census population
- Inter-Census pop. estimate
- Housing data
- Poverty data
- Population projections

**Built Environment**
- Roads
- Airports
- Rail Lines
- Real Property Data
- Schools location
- Hospitals

**Health and Exposure**
- Hospital Discharge
- Emergency Department
- Live Births and Mortality
- Cancer
- Birth Defects
- Childhood blood lead levels

**Political / Postal Boundaries**
- County
- Town
- Legislative districts
- Zip Code

**Natural Environment**
- Land use/land cover
- High resolution aerial imagery
- Geology and hydrology
- Topography
Environmental Public Health Tracker

About Birth Defects
(Also called congenital malformations or congenital anomalies)

Collecting and sharing good information about when and where birth defects happen is a first step in understanding how they might be related to the environment. Looking at patterns of birth defects rates can help health officials plan services and create ideas for research into environmental causes of birth defects. The New York State Department of Health's Congenital Malformations Registry (CMR) stores data on children with birth defects in New York State.

About one out of every 33 babies is born with a birth defect. Birth defects are the leading cause of infant death and babies with birth defects have a greater chance of illnesses and long-term disabilities than babies without birth defects. Lifetime costs to care for a person with a birth defect can be more than $500,000.

- Learn more about 48 birth Defects. Definitions and information links for 48 reported birth defects.

Risk Factors

Doctors and researchers know how certain birth defects occur, but there are a large number of birth defects that are not well understood. Very few birth defects have a definite link to environmental hazards, although possible links have not been well studied. It is likely that most birth defects happen for many reasons, not just one reason.

Known and probable risk factors for birth defects include the following:
- Smoking, alcohol and other drugs
- Poor nutrition and/or health (such as low levels of folic acid, obesity and poorly controlled diabetes)
- Medications (prescription & over-the-counter)
- Toxic chemicals & their fumes (such as lead, paint and paint thinner, gasoline, pesticides, and second-hand smoke)
- Infectious agents (such as rubella and toxoplasmosis)
- Radiation (X-rays)

Birth Defects Research

Prevention for Women Planning to Have Children

- Have regular medical checkups
- Eat healthy foods and maintain a healthy weight
- Make sure that medical conditions like diabetes are under control
- Take a vitamin with folic acid every day
Comparison of BD Prevalence by County

Specific Birth Defects Within a County

Children Born With Birth Defects in New York County (Manhattan)

<table>
<thead>
<tr>
<th>Birth Defect</th>
<th>Children</th>
<th>Prevalence per 10,000 Live Births</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Birth Defects</td>
<td>1,428</td>
<td>148.3</td>
</tr>
<tr>
<td>Anencephaly</td>
<td>2</td>
<td>0.2 *</td>
</tr>
<tr>
<td>Aniridia</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Anophthalmia/Hypophthalmia</td>
<td>5</td>
<td>0.5 *</td>
</tr>
<tr>
<td>Anotia/Hyotia</td>
<td>3</td>
<td>0.3 *</td>
</tr>
<tr>
<td>Aortic Valve Stenosis</td>
<td>12</td>
<td>1.2</td>
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<tr>
<td>Atrial Septal Defect</td>
<td>338</td>
<td>33.5</td>
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<tr>
<td>Biliary Atresia</td>
<td>6</td>
<td>0.6 *</td>
</tr>
<tr>
<td>Bladder Exstrophy</td>
<td>2</td>
<td>0.2 *</td>
</tr>
<tr>
<td>Choanal Atresia</td>
<td>13</td>
<td>1.3</td>
</tr>
<tr>
<td>Cleft Lip with or without Cleft Palate</td>
<td>51</td>
<td>5</td>
</tr>
<tr>
<td>Cleft Palate without Cleft Lip</td>
<td>45</td>
<td>4.5</td>
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<tr>
<td>Cloacal Exstrophy/Persistent Cloaca</td>
<td>0</td>
<td>0</td>
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<td>Coarctation of Aorta</td>
<td>32</td>
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<tr>
<td>Common Truncus</td>
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<td>Congenital Cataract</td>
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<tr>
<td>Craniosynostosis</td>
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</table>
NYS EPHT Public Portal

Allows Export of County Level Data in comma-separated values (CSV) Format

<table>
<thead>
<tr>
<th>County Name</th>
<th>Total Live</th>
<th>Total Num</th>
<th>Total Pren</th>
<th>Anencephal</th>
<th>Aniridia</th>
<th>Anophthalmia</th>
<th>Anotia/Mi Aortic Vah</th>
<th>Atrial Sept Biliary Atra Bla</th>
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<td>6</td>
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<td>1,051</td>
<td>196.8</td>
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<td>0</td>
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<td>0</td>
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<td>FRANKLIN</td>
<td>2,347</td>
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<td>140.6</td>
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<td>GREENE</td>
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<td>135.1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
Tier 2 – Health Commerce System
NYS EPHT Secure Portal

Local and State Public Health Agencies
Although you have a valid HCS user account, access to this area must be approved by the New York State Department of Health. Please complete the form and click on the SEND button below. Note: All fields are required.

After clicking SEND button below, you will receive a response by e-mail within one week.

EPHT Secure Portal Request for Access

“Role-Based Access”
The New York State Environmental Public Health Tracking (EPHT) Secure Portal is intended for use by scientists, program staff and policy makers of the New York State (NYS) Department of Health and NYS county and local health departments. It makes data available at a finer resolution than what are available on the public portal (such as ZIP Code level disease counts or county rates stratified by sex or race). It will also provide mapping and discovery capabilities to track trends, promote public health planning and control, and help efforts to protect New York State’s communities.

Some datasets are available to anyone with access to the Environmental Public Health Tracking Secure Portal, while others require the user to request access from the data owners. All users are expected to honor state and federal statutes regarding confidentiality and release of health information.

Please select a dataset to begin your query.

Environment

- Ambient Air Pollution
- Drinking Water
- Environmental Facilities and Cancer Mapping
- National Toxic Substance Incident Program (NTSIP)

Health

- Birth Defects
- Birth Outcomes
- Hospitalizations

Access beyond this page may be restricted to approval by program area.
# New York State Birth Defects (Congenital malformations)

**FGDC Metadata**

<table>
<thead>
<tr>
<th>Description</th>
<th>Spatial</th>
<th>Data Structure</th>
<th>Data Quality</th>
<th>Data Source</th>
<th>Data Distribution</th>
<th>Metadata</th>
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</thead>
</table>

## Citation

**Title:** New York State Birth Defects (Congenital malformations)

**Originators:** Congenital Malformations Registry

**Publication date:** 20110214

## Description

**Abstract:** This dataset contains counts for 45 congenital malformations among New York State live births. These data are stratified by birth year, maternal age group, maternal ethnicity/race and infant sex. Birth defects are also grouped by 11 organ systems.

**Purpose:** To provide data for the National Environmental Public Health Tracking Network consistent with the guidance for creating birth defects rates that follow Nationally Consistent Data and Measures (NCDMs).

**Supplemental information:** Data has been de-identified to protect patient confidentiality. Birth defects are selected based on a specific list of ICD-9-CM codes and narratives. Further information about the Congenital Malformations Registry can be obtained at: [http://www.health.state.ny.us/diseases/congenital_malformations/cmrhome.htm](http://www.health.state.ny.us/diseases/congenital_malformations/cmrhome.htm)

## Point Of Contact

**Person:** Congenital Malformations Registry

**Organization:** Bureau of Environmental and Occupational Epidemiology, NYSDOH

**Phone:** 518-402-7990

**Fax:** 518-402-7969

**Email:** cmr@health.state.ny.us

**Hours of service:** 8:30 AM - 4:30 PM

**Address type:** Mailing and Physical

**Address:** 547 River Street; Room 200

**City:** Troy

**State or Province:** NY

**Postal code:** 12180

**Country:** United States Of America
NYS EPHT Secure Portal
Birth Defects Query

Environmental Public Health Tracking Secure Portal

Birth Defects Data Query: Part 1

Step 1: Select ONE birth defects group:
- Individual Birth Defects

Step 2: Select ONE or MORE Birth Defects/Organ System:
- All 45 Birth Defects
- Anencephaly
- Spina bifida (w/o Anencephaly)
- Hypoplastic left heart syndrome

Step 3: Select geographic scale:
- County
- Zip Code

Step 4: Select ONE group variable:
- Infant's Sex
- Mother's Age
- Mother's Race and Ethnicity
- None

Step 5: Select year(s) of birth:
- **All Years**
- 2000
- 2001
- 2002

Note: Zip Code Level Queries will not allow individual year selection
<table>
<thead>
<tr>
<th>Query Summary:</th>
<th></th>
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<tbody>
<tr>
<td>Health Data</td>
<td>Individual Birth Defects</td>
</tr>
<tr>
<td>Birth Defects</td>
<td>All 45 Birth Defects</td>
</tr>
<tr>
<td>Geographic Scale</td>
<td>County</td>
</tr>
<tr>
<td>Group Variable</td>
<td>Infant’s Sex</td>
</tr>
<tr>
<td>Year(s) of Birth</td>
<td>2000-2005</td>
</tr>
<tr>
<td>County or Counties of patient</td>
<td>All New York State</td>
</tr>
<tr>
<td>residence</td>
<td></td>
</tr>
<tr>
<td>Display Output</td>
<td>Map (All group variables)</td>
</tr>
</tbody>
</table>

Submit
Average Annual Birth Defect Rate per 10,000 Population:
SEX Group: All group
Years: 2000-2007
## Prevalence of Selected Birth Defects in New York

<table>
<thead>
<tr>
<th>Year</th>
<th>Birth Defect</th>
<th>Female</th>
<th></th>
<th>Male</th>
<th></th>
<th>Sex Unknown</th>
<th></th>
<th>Total</th>
<th></th>
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<tbody>
<tr>
<td></td>
<td></td>
<td>No. of Birth Defects</td>
<td>Rate per 1000 Births</td>
<td>No. of Birth Defects</td>
<td>Rate per 1000 Births</td>
<td>No. of Birth Defects</td>
<td>Rate per 1000 Births</td>
<td>No. of Birth Defects</td>
<td>Rate per 1000 Births</td>
</tr>
<tr>
<td>New York State</td>
<td>2000 - Anencephaly</td>
<td>6</td>
<td>0.05</td>
<td>10</td>
<td>0.08</td>
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<td>6</td>
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</tbody>
</table>
Step 6: Select county or counties: Please note that data are not available in all areas, or for every year. Because of this, your final query may not be processed for some or all of the areas you selected.

- You may select more than one county by holding down the Ctrl key while clicking on subsequent counties.
- You may select more than one county by clicking on individual counties.
EPHT Secure Portal Displays
Birth Defects Query

Tables, charts & maps can be displayed
Displaying Birth Defects Prevalence By Zip Codes

- New York State Live Birth data for years 2001 through 2005
- Geographical scale: ZIP Code
- # of ZIP Code: ~1590
- Range of # of births: 0-11,179 (5 yrs)
- Average # of births: 783 / ZIP Code (5 yrs)
Aggregate Zip Codes to Protect Confidentiality

No Aggregation
1590 Zip Codes

100 live births
1133 Regions

250 live births
872 Regions

500 live births
667 Regions
Aggregation Tool

Original Block Data †

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<th>Block</th>
<th>Cases</th>
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<tr>
<td>122300/2005</td>
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<td>014500/3005</td>
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Regions

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</tr>
<tr>
<td>122300/2005</td>
<td>11</td>
<td>A</td>
</tr>
<tr>
<td>014500/3005</td>
<td>3</td>
<td>B</td>
</tr>
<tr>
<td>014500/3007</td>
<td>4</td>
<td>B</td>
</tr>
<tr>
<td>014500/3008</td>
<td>0</td>
<td>B</td>
</tr>
<tr>
<td>014500/3009</td>
<td>1</td>
<td>B</td>
</tr>
<tr>
<td>014500/3010</td>
<td>15</td>
<td>B</td>
</tr>
<tr>
<td>103202/2001</td>
<td>8</td>
<td>C</td>
</tr>
<tr>
<td>103202/2002</td>
<td>6</td>
<td>C</td>
</tr>
</tbody>
</table>

† Simulated data
Birth Defects

Step 1: Select ZIP Code(s) of patient residence:

- If you select a county in this list, you will be provided with data for all ZIP Codes that exist in the county, in whole or in part, including "point" ZIP Codes that cannot be mapped (such as institutions like colleges and prisons or rural Post Offices where patrons pick up their own mail).

- If you select individual ZIP Codes by clicking on the map below, you will be provided with data only for those ZIP Codes.
### Example Output – Zip Code Level Query

#### Prevalence of Selected Birth Defects in New York

<table>
<thead>
<tr>
<th>Year</th>
<th>Birth Defect</th>
<th>Female</th>
<th>Male</th>
<th>Sex Unknown</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>No. of Birth Defects</td>
<td>Rate per 1000 births</td>
<td>No. of Birth Defects</td>
<td>Rate per 1000 births</td>
</tr>
<tr>
<td>2000</td>
<td>Genitourinary(BPA=752.x-753.x)</td>
<td>412</td>
<td>3.27</td>
<td>2,691</td>
<td>20.30</td>
</tr>
<tr>
<td></td>
<td>Musculoskeletal(BPA=754.x-756.x)</td>
<td>1,002</td>
<td>9.05</td>
<td>1,234</td>
<td>9.91</td>
</tr>
<tr>
<td>2001</td>
<td>Genitourinary(BPA=752.x-753.x)</td>
<td>400</td>
<td>3.33</td>
<td>2,757</td>
<td>21.24</td>
</tr>
<tr>
<td></td>
<td>Musculoskeletal(BPA=754.x-756.x)</td>
<td>1,195</td>
<td>9.66</td>
<td>1,232</td>
<td>9.49</td>
</tr>
<tr>
<td>2002</td>
<td>Genitourinary(BPA=752.x-753.x)</td>
<td>455</td>
<td>3.72</td>
<td>2,812</td>
<td>21.80</td>
</tr>
<tr>
<td></td>
<td>Musculoskeletal(BPA=754.x-756.x)</td>
<td>1,247</td>
<td>10.19</td>
<td>1,236</td>
<td>9.92</td>
</tr>
<tr>
<td>2003</td>
<td>Genitourinary(BPA=752.x-753.x)</td>
<td>493</td>
<td>4.00</td>
<td>2,745</td>
<td>21.60</td>
</tr>
<tr>
<td></td>
<td>Musculoskeletal(BPA=754.x-756.x)</td>
<td>1,256</td>
<td>10.19</td>
<td>1,308</td>
<td>10.28</td>
</tr>
<tr>
<td>2004</td>
<td>Genitourinary(BPA=752.x-753.x)</td>
<td>402</td>
<td>4.01</td>
<td>2,899</td>
<td>23.01</td>
</tr>
<tr>
<td></td>
<td>Musculoskeletal(BPA=754.x-756.x)</td>
<td>1,192</td>
<td>9.92</td>
<td>1,299</td>
<td>10.31</td>
</tr>
<tr>
<td>2005</td>
<td>Genitourinary(BPA=752.x-753.x)</td>
<td>506</td>
<td>4.28</td>
<td>2,933</td>
<td>23.58</td>
</tr>
<tr>
<td></td>
<td>Musculoskeletal(BPA=754.x-756.x)</td>
<td>1,304</td>
<td>11.03</td>
<td>1,380</td>
<td>11.10</td>
</tr>
</tbody>
</table>

#### Aggregated Region

<table>
<thead>
<tr>
<th>Aggregated Region</th>
<th>Birth Defect</th>
</tr>
</thead>
<tbody>
<tr>
<td>12009nm All</td>
<td>Genitourinary(BPA=752.x-753.x)</td>
</tr>
<tr>
<td>12203nm All</td>
<td>Musculoskeletal(BPA=754.x-756.x)</td>
</tr>
</tbody>
</table>

**Notes:**
- Some ZIP Codes are within county boundaries. The values provided are for the entire ZIP Code, not just the portion in this county.
- Some valid ZIP Codes are enclosed within other ZIP Codes (such as buildings, institutions, or rural Post Offices).
- There are 0 or less birth defects in the sub-group for indicated ZIP Code.

**Birth defects data source:** Congenital Malformation Registry (CMR), NYSDOH.

**Zip Code population data source:** The Nielsen Company, Claritas Solutions, Ithaca NY.

- List of ZIP Code included in query results.
- List included user selected ZIP Code along with additional ZIP Code in selected region.
NYS EPHT Secure Portal

**BEOE - EPHT**
- Syni-An Hwang
- Tom Talbot
- Sanjaya Kumar
- Neil Muscatiello
- Melissa Frisbie

**ISHSG - BHNSM**
- Linh Le
- Kathryn Schmit
- Xiaohang Wang
- Joseph Pianella

**BEOE – Congenital Malformations Registry**
- Charlotte Druschel
- Ying Wang
- Zhen Tao
- CMR Staff
Contact Information

Philip Cross
Assistant Director
Bureau of Environmental & Occupational Epidemiology
Center for Environmental Health
New York State Department of Health

Flanigan Square
547 River Street, Room 200
Troy, New York 12180-2216

Phone: 518-402-7950
E-Mail: pkc02@health.state.ny.us