Birth Defects Surveillance in New York State

Edward F. Fitzgerald, PhD
Francis Boscoe, PhD
Philip Cross, MS
Charlotte Druschel, MD
Thomas Talbot, MSPH
Established October, 1982

Recognition of the environment as a potential etiologic factor for birth defects (Love Canal)

Reporting to the Registry is mandated by Public Health Law - State Sanitary Code 22.3
Population Coverage: Statewide approximately 260,000 to 300,000 births annually

Designed for surveillance, research & to provide data to health programs to aid in the development of needs assessment

Full time staff - 8
Grant Funded positions - 9
Children diagnosed up to 2 years of age who were born or reside in New York State with a major congenital malformation, chromosomal anomaly or persistent metabolic defect.

*List of reportable ICD-9-CM codes available on NYSDOH Public WebSite:  [www.health.state.ny.us](http://www.health.state.ny.us)
Congenital Malformations Registry
Surveillance System
Recording Malformations

1983-1991: Only ICD codes were included in the CMR database

1992-1998: ICD codes & CDC modified version of the British Pediatric Association (B PA) codes

1998-present: Reported ICD codes, BPA codes and malformation narratives
## Confidential Case Report Form 2002

### Child's Information

<table>
<thead>
<tr>
<th>Field</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>PAT No.</td>
<td></td>
</tr>
<tr>
<td>Child's Name</td>
<td></td>
</tr>
<tr>
<td>First</td>
<td></td>
</tr>
<tr>
<td>M.I.</td>
<td></td>
</tr>
<tr>
<td>Medical Record Number</td>
<td></td>
</tr>
</tbody>
</table>

### Address

<table>
<thead>
<tr>
<th>Street</th>
<th>City</th>
<th>State</th>
<th>Zip Code</th>
</tr>
</thead>
</table>

### Date of Birth (Month/Day/Year)

<table>
<thead>
<tr>
<th>Month</th>
<th>Day</th>
<th>Year</th>
</tr>
</thead>
</table>

### Birth Status

- [ ] Live
- [ ] Stillborn

### Birthweight (grams)

<table>
<thead>
<tr>
<th>Weight</th>
</tr>
</thead>
</table>

### Sex

- [ ] Male
- [ ] Female
- [ ] Undesignated

### Race

- [ ] White
- [ ] Black or African American
- [ ] American Indian
- [ ] Asian
- [ ] Pacific Islander
- [ ] Other

### Marital Status

- [ ] Single
- [ ] Married
- [ ] Divorced
- [ ] Widowed

### Birth Place

<table>
<thead>
<tr>
<th>Hospital</th>
<th>City</th>
<th>State</th>
<th>Zip Code</th>
</tr>
</thead>
</table>

### Date of Discharge (Month/Day/Year)

<table>
<thead>
<tr>
<th>Month</th>
<th>Day</th>
<th>Year</th>
</tr>
</thead>
</table>

### Diagnoses

1.  
2.  
3.  
4.  
5.  
6.  
7.  
8.  
9.  
10.  

### Parent's Information

#### Mother's Name

<table>
<thead>
<tr>
<th>Last</th>
<th>First</th>
<th>M.I.</th>
<th>Maiden Name</th>
</tr>
</thead>
</table>

#### Father's Name

<table>
<thead>
<tr>
<th>Last</th>
<th>First</th>
<th>M.I.</th>
</tr>
</thead>
</table>

#### Date of Birth (Month/Day/Year)

- [ ] Mother
- [ ] Father

#### Social Security Number

- [ ] Mother
- [ ] Father
The New York State Department of Health (NYSDOH) has developed the Health Provider Network (HPN) as a secure system for electronically collecting and distributing health related data. NYSDOH uses techniques which ensures that data exchanges between the HPN and providers are done in a secure fashion and also provide security for data on the HPN.
State of New York
Department of Health
Health Provider Network
George E. Pataki, Governor
Antonia C. Novello, M.D., M.P.H., Dr.P.H.,
Commissioner of Health

Best viewed with Netscape® Version 4.06 or higher

HPN Home Page
Revised 11/12/2001

*IMPORTANT*

Media on Demand - Archived Broadcasts from the CDC
AS OF 12/19/2001

What's New
Looking for the HPN Documents for HPN Access? - go to the UPDATED HPN Coordinator's page, 12/12/2001

Hot Topics
Bioterrorism Readiness on the NYSDOH public web site.
The Physician's Page with links to the Physician Profile Survey - Physicians complete, review, and update their Physician Profile information - forms and other physician related information.

HPN TOPICS

Data Retrieval
ECLRS, NYS Community Health Data Set, SPARCS Data

Data Submission
Upload and Report data online to the various program areas of the Health Department

Health Alert Network
The Health Alert Network (HAN) project brings together information of interest to organizations with disaster preparedness responsibilities. This website is designed for public and private health providers and first responders.

Physician's Page
NYS Physician Profile and other Information for Physician's on the HPN

Programs
NYSDOH program area information (e.g. Health Care Financing, Continuing Care, Managed Care etc.), plus: enter and submit data online, view and search databases.
Welcome to New York State's Congenital Malformations Registry

Select from the tasks below:

- Health Provider Network Reporting System
  - Enter confidential case reports
  - Upload case reports data
  - Complete uploaded case reports
  - Edit/View unprocessed case reports
  - View/Search all case reports
  - View the transaction log

- Monthly counts of reports received for 2002
- Yearly counts of reports received for 1998-2002
- CMR additional information requests
- View/Edit CMR hospital contact information
- Contact the CMR
- CMR Specific Tasks
Example of a drop down menu – hospital of birth
Error message received when a required field is missing
The CMR is a “passive” registry with mandatory hospital reporting.

Hospital discharge data linkage has enabled the CMR to become - PASSIVE AGGRESSIVE.
Congenital Malformations Registry Audits Using SPARCS Discharge Data

SPARCS inpatient data monthly subset
  – current New York State resident
  – age at discharge of 2 years or less
  – diagnosed with major malformation

Matching Criteria
  – Hospital Permanent Facility Identifier (PFI)
  – Date of birth
  – Infant’s medical record number (substrings)
  – Mother’s medical record number (substrings)
  – Infant’s patient control number (SPARCS)
### Audit Of 1998-1999 Births

#### Select Hospital You Want To Audit And Press Print Audit Report.

<table>
<thead>
<tr>
<th>Hospital Name</th>
<th>City</th>
</tr>
</thead>
<tbody>
<tr>
<td>Albany Medical Center Hospital</td>
<td>Albany</td>
</tr>
<tr>
<td>AMC-South Clinical Campus</td>
<td>Albany</td>
</tr>
<tr>
<td>St. Peter's Hospital</td>
<td>Albany</td>
</tr>
<tr>
<td>St. Margaret's Center for Children</td>
<td>Albany</td>
</tr>
<tr>
<td>Jones Memorial Hospital</td>
<td>Wellsville</td>
</tr>
<tr>
<td>Lourdes Hospital</td>
<td>Binghamton</td>
</tr>
<tr>
<td>United Health Services</td>
<td>Johnson City</td>
</tr>
<tr>
<td>Olean General Hospital</td>
<td>Olean</td>
</tr>
<tr>
<td>Tri-County Memorial Hospital</td>
<td>Gowanda</td>
</tr>
<tr>
<td>Auburn Memorial Hospital</td>
<td>Auburn</td>
</tr>
<tr>
<td>Brooks Memorial Hospital</td>
<td>Dunkirk</td>
</tr>
<tr>
<td>Women's Christian Assn Hospital</td>
<td>Jamestown</td>
</tr>
<tr>
<td>Westfield Memorial Hospital</td>
<td>Westfield</td>
</tr>
</tbody>
</table>

**Congenital Malformations Registry**

Albany Medical Center Hospital has 55 possibly unreported children with one or more malformations. Do you want to print this report?

[Yes] [No]
Improved completeness of reporting - approximately 33% of 1996-1997 reports ascertained through monitoring.
Significant Clusters of Obstructive Renal Defects Suggestive of Regional Differences in Use of Ultrasound

No overlapping clusters; maximum of 5% of births captured by a cluster
EPHT Demonstration Project: General Goal

- Link Public Water Supply Monitoring Data with Birth Outcome Data to Identify Unusual Patterns and Trends in Time and Space Regarding Exposure and/or Disease
Background

- Disinfection of Public Water Supply through Chlorination Yields Disinfection Byproducts (DBPs)
  - Trihalomethanes (THMs), Haloacetic Acids (HAAs)
  - Depends on Source Water Characteristics Such as Level of Organic Matter
- 82% of Water Supply Systems Serving \( \geq 10,000 \) Persons in New York Use Chlorination
Background

- **Epidemiological Studies Have Shown Positive though Weak Associations between DBPs and Adverse Birth Outcomes**
  - Low Birth Weight
  - Intrauterine Growth Retardation
  - Certain Congenital Malformations

- **Limitations**
  - Small Sample Size
  - Lack of Measured Contaminant Levels
Environmental Hazard Database

- **State Drinking Water Information System (SDWIS)**
  - Analytical Results for Total THMs and 5 HAAs
    - Mandated Quarterly Monitoring
    - Some Systems Monitor Monthly
  - Digitized Supply Area Boundaries
  - Includes Systems Serving >= 10,000 Persons
    - Small Systems to be Added Beginning in 2004
Health Outcome Databases

- **Congenital Malformations Registry (CMR)**
  - Total Defects
  - Selected Major Defects

- **Birth Certificates**
  - Low Birth Weight
  - Intrauterine Growth Retardation
  - Small for Gestational Age
Data Linkage

- **Geocode Maternal Address at Birth from CMR and Birth Certificate Records**
  - Longitude and Latitude Determined Using Automated Enterprise Geocoding Engine
- **Use Geocoded Address to Assign Each Health Record To Specific Water District**
  - Use “Point in Polygon Matching” with GIS
Exposure Assessment

- Assume Water District At Birth Is a Proxy for DBP Exposure Throughout Pregnancy
- Each Pregnancy Will Have 3 or 4 Associated DBP Measurements
  - Measurements Not Evenly Spaced in Time (e.g., two “quarterly” measurements may be taken in the same week – March 31 and April 1)
  - Will Evaluate Mean and Maximum DBP Level as Indicators of Average and Peak Exposure
  - First Trimester Measurement Is Most Important for Major Congenital Malformations
Data Visualization and Analysis

- Use Maps, Spatial Statistics and Other Surveillance Methods to Detect Unusual Patterns or Trends in Time and Space for DBPs and/or Birth Outcomes
- Use Spatial Regression Techniques to Assess Associations between DBPs and Birth Outcomes
Current Status

- **Finalizing Work Plan**
  - Solicit Input from Planning Consortium at Next Meeting (April 30)
- **Currently Hiring Project Staff**
- **Enterprise Geocoding Engine Ready for Testing**
- **Improving Electronic Reporting of Both Malformation Registry and Water Monitoring Data**