

Birth Defects Surveillance in New York State

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Congenital Malformations Registry Background



- 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

Congenital Malformations Registry Background

**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

**Striving for
Healthy
Births**



Congenital Malformations Registry Case Definition

**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**

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 (BPA) codes

1998-present: Reported ICD codes, BPA codes and malformation narratives

Confidential Case Report Form 2002



Congenital Malformations Registry Confidential Case Report

New York State Department of Health
Bureau of Environmental and Occupational Epidemiology

Type or print clearly using blue or black ink.

Child's Information		PFI No.	Medical Record Number	
Child's Name Last		First	M.I.	(DOH USE ONLY)
If child has been identified by another name(s), enter the name(s)				
Address Street		City	State	Zip Code
Date of Birth (month/day/year) ___/___/___	Birth Status <input type="checkbox"/> Live <input type="checkbox"/> Still	Birthweight (grams)	Sex <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Undesignated	
Race <input type="checkbox"/> White <input type="checkbox"/> Black or African American <input type="checkbox"/> American Indian/ Alaskan Eskimo <input type="checkbox"/> Asian/Pacific Islander <input type="checkbox"/> Unknown				Hispanic <input type="checkbox"/> Yes <input type="checkbox"/> No
Plurality <input type="checkbox"/> Single <input type="checkbox"/> Twin <input type="checkbox"/> Triplet Other, specify _____		If a multiple birth, specify birth order <input type="checkbox"/> 1st <input type="checkbox"/> 2nd <input type="checkbox"/> 3rd Other, specify _____		
Born at this facility <input type="checkbox"/> Yes <input type="checkbox"/> No	If not born at this facility: Hospital _____ City _____ State _____ Zip Code _____			
Date of Discharge (month/day/year) ___/___/___	Deceased <input type="checkbox"/> Yes <input type="checkbox"/> No	If deceased, date of death (month/day/year) ___/___/___		Foster/Adopted <input type="checkbox"/> Foster <input type="checkbox"/> Adopted <input type="checkbox"/> No
Diagnostic Information				
Chromosome Studies If yes, Karyotype _____ If pending, cytogenetic lab _____				
Diagnoses: 1) _____ 2) _____ 3) _____ 4) _____ 5) _____ 6) _____ 7) _____ 8) _____ 9) _____ 10) _____				
Parent's Information				
Mother's Name Last		First	M.I.	Maiden Name
Date of Birth (month/day/year) ___/___/___		Social Security Number _____ - _____ - _____		
Father's Name Last		First	M.I.	
Date of Birth (month/day/year) ___/___/___		Social Security Number _____ - _____ - _____		

Congenital Malformations Registry Internet Reporting Option

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

HPN Home Page

Revised 11/12/2001

Best viewed with [Netscape® Version 4.06 or higher](#)

* IMPORTANT *	<p align="center"> Media on Demand - Archived Broadcasts from the CDC AS OF 12/19/2001 </p>
What's New	<p>Looking for the HPN Documents for HPN Access? - go to the UPDATED HPN Coordinator's page, 12/12/2001</p>
Hot Topics	<p>Bioterrorism Readiness on the NYSDOH public web site.</p> <p>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.</p>

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

CMR Home Page on the HPN

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](#)

Date of Birth (mm/dd/yyyy):

Birthweight (grams):

Date of Diagnosis (mm/dd/yyyy):

Date of Discharge (mm/dd/yyyy):

Sex:

Race:

Hispanic:

Foster/Adopted:

Deceased:

Date of Death (mm/dd/yyyy):

Autopsy:

Born at this facility:

If not born at this facility, hospital of birth:

Birth Status:

Plurality:

If not a single birth, specify birth order:

- PFI 0739: A. O. Fox Memorial Hospital (Oneonta)
- PFI 0002: AMC- South Clinical Campus (Albany)
- PFI 0324: Adirondack Medical Center (Saranac Lake)
- PFI 0001: Albany Medical Center Hospital (Albany)
- PFI 3058: Albert Einstein College of Medicine (Bronx)
- PFI 0325: Alice Hyde Memorial Hospital (Malone)
- PFI 0482: Amsterdam Memorial Hospital (Amsterdam)
- PFI 0699: Arden Hill Hospital (Goshen)
- PFI 0116: Arnot Ogden Medical Center (Elmira)
- PFI 0085: Auburn Memorial Hospital (Auburn)
- PFI 0746: Bassett Health Care (Cooperstown)
- PFI 0848: Bellevue . . . The Woman's Hospital (Niskayuna)
- PFI 1438: Bellevue Hospital Center (Manhattan)
- PFI 0989: Benedictine Hospital (Kingston)
- PFI 0280: Bertrand Chaffee Hospital (Springville)
- PFI 1439: Beth Israel Medical Center (New York)
- PFI 1138: Blythedale Children's Hospital (Valhalla)
- PFI 1165: Bronx Municipal Hospital Center (Bronx)
- PFI 1178: Bronx-Lebanon Hosp.-Concourse Div. (Bronx)

Example of a drop down menu – hospital of birth

Diagnostic Information:

Chromosome Studies:

If yes, Karyotype:

Parent's Information: **Error message received when a required field is missing**

Mother's Last Name:
First Name:
Middle Initial:
Maiden Name:
Date of Birth (mm/dd/yyyy):
Age:
Social Security Number:

bhns03.health.state.ny.us - [JavaScript Application]

 Infant's Last Name is a required field.

OK

Father's Last Name:
First Name:
Middle Initial:
Date of Birth (mm/dd/yyyy):
Age:
Social Security Number:

Send to CMR Clear Form

Congenital Malformations Registry Hospital Discharge Data Linkage

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.

	St. Vincent's	
000001	Albany Medical Center Hospital	Albany
000002	AMC- South Clinical Campus	Albany
000005	St. Peter's Hospital	Albany
000019	St. Margaret's Center for Children	Albany
000039	Jones Memorial Hospital	Wellsville
000043	Lourdes Hospital	Binghamton
000058	United Health Services	Johnson City
000066	Olean General Hospital	Olean
000074	Tri-County Memorial Hospital	Gowanda
000085	Auburn Memorial Hospital	Auburn
000098	Brooks Memorial Hospital	Dunkirk
000103	Women's Christian Assn Hospital	Jamestown
000111	Westfield Memorial Hospital	Westfield
000116	Arnot O	
000118	St. Jos	

Print Audit Report

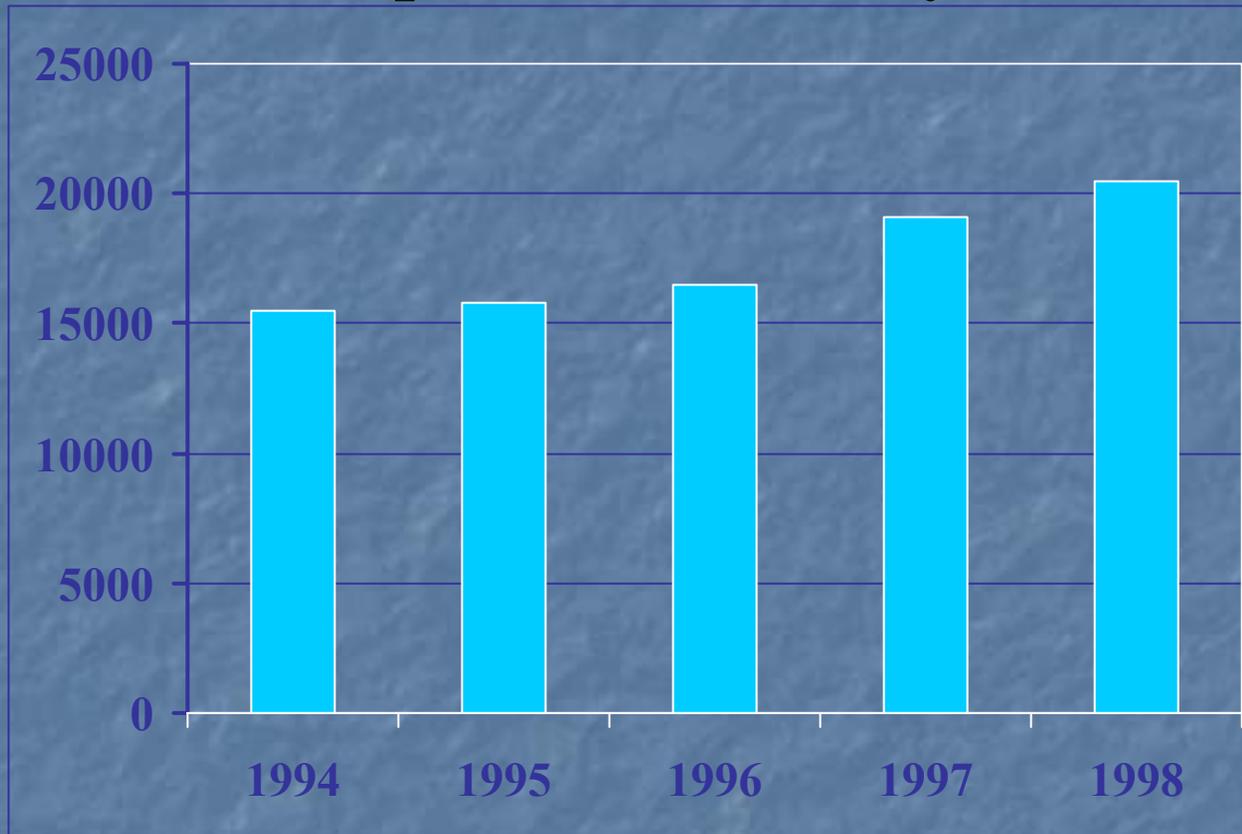
Congenital Malformations Registry

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

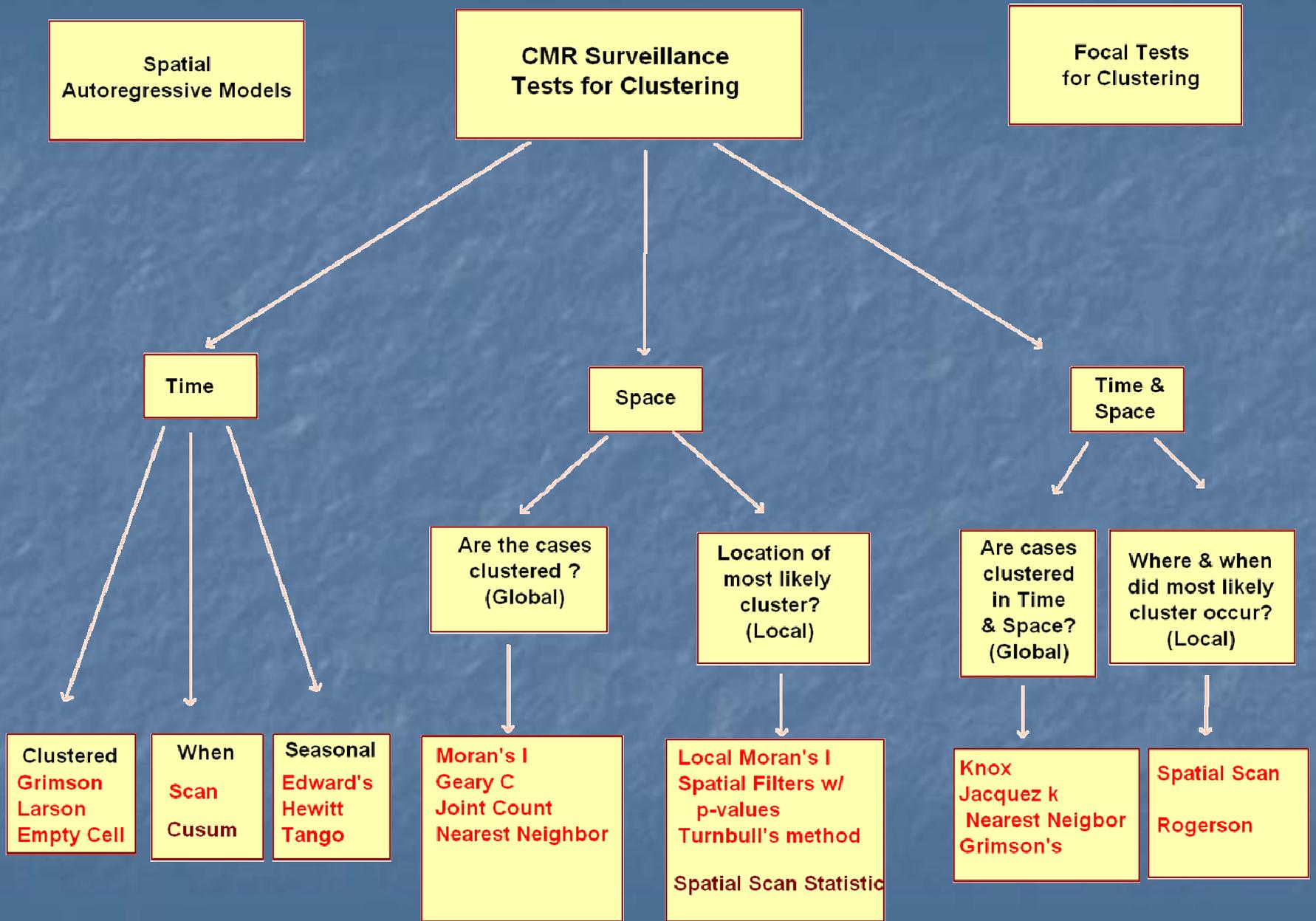
Yes No

CMR - SPARCS LINK AUDIT RESULTS

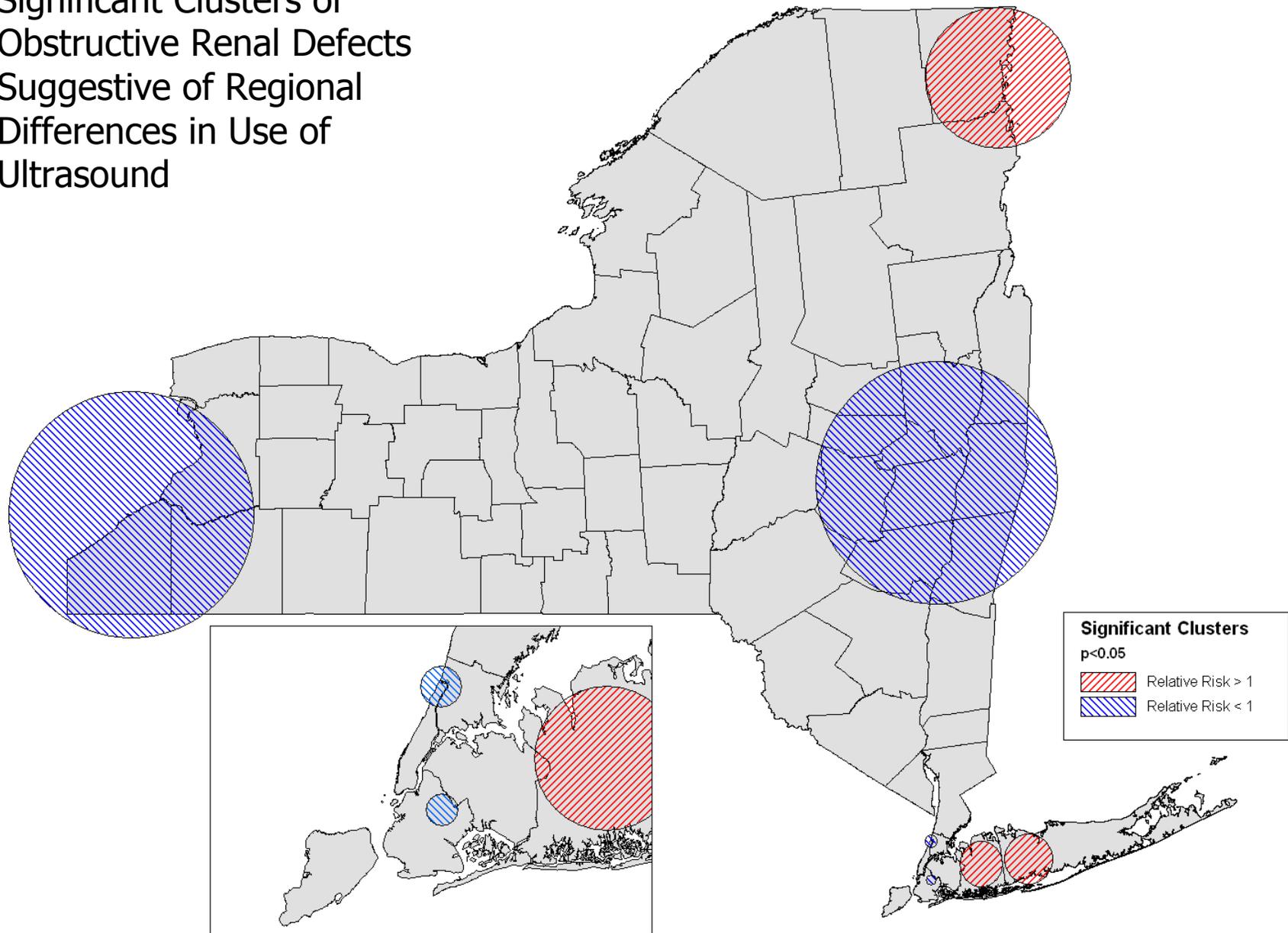
New Reports Received by Year



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

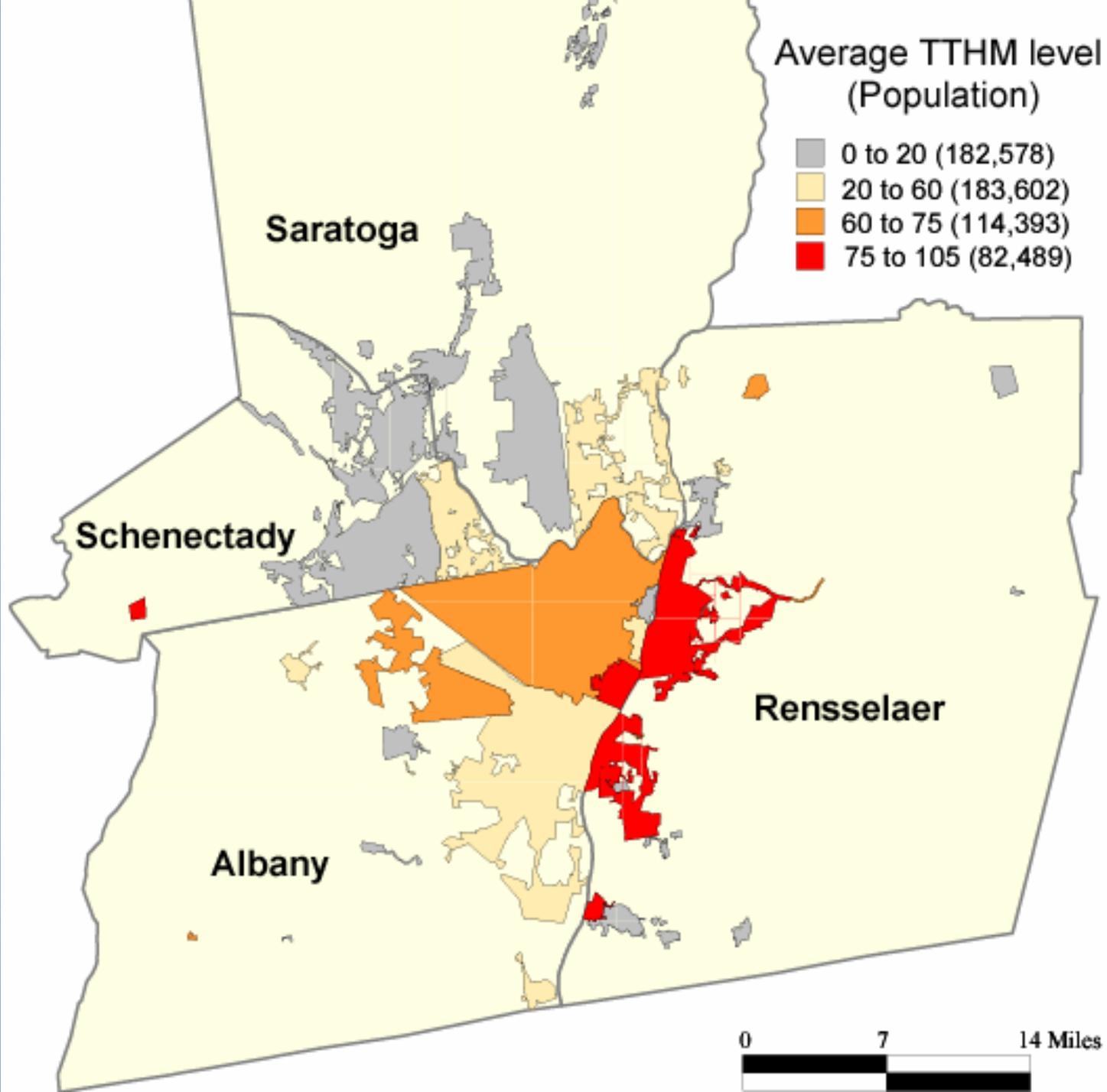
- **Disinfection of Public Water Supply through Chlorination Yields Disinfection Byproducts (DBPs)**
 - **Trihalomethanes (THMs), Haloacetic Acids (HAAs)**
 - **Depends on Source Water Characteristics Such as Level of Organic Matter**
- **82% of Water Supply Systems Serving $\geq 10,000$ Persons in New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