

NYS Congenital Malformations Registry Converting to a Web-based System



**National Birth Defects Prevention Network
Nashville, TN
February 23-25, 2009**

NYS Congenital Malformations Registry Converting to a Web-based System

Topics

Congenital Malformations Registry (CMR) Background

Overview of the CMR Web-based System

Example Applications

Resources & Staff Required

Tips & Recommendations

Improvements in Data Quality and Timeliness



Congenital Malformations Registry Reporting

Statewide - approximately **250,000** to **300,000** births annually

Registry receives approximately **20,000** reports per year from 163 hospitals statewide on approximately **12,000** children

Cases can be diagnosed with **20+** major malformations

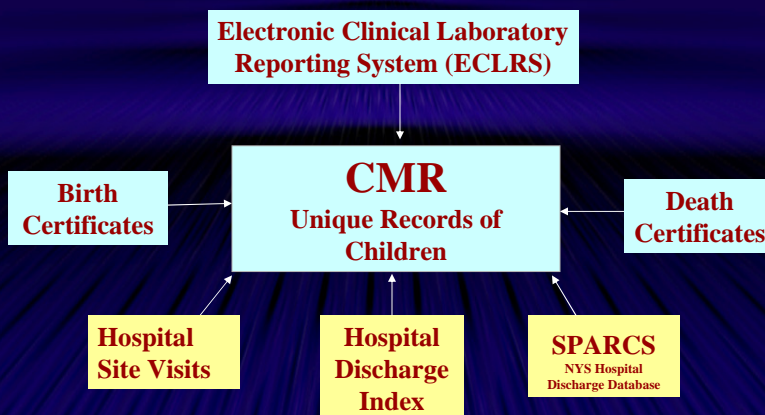
Cases can be reported multiple times from one or more hospitals & by physicians up to the age of 2

Reports from all sources are maintained and linked with a unique case number



Electronic Card File
1980's "Technology"

Congenital Malformations Registry Data Linkage & Additional Data Sources

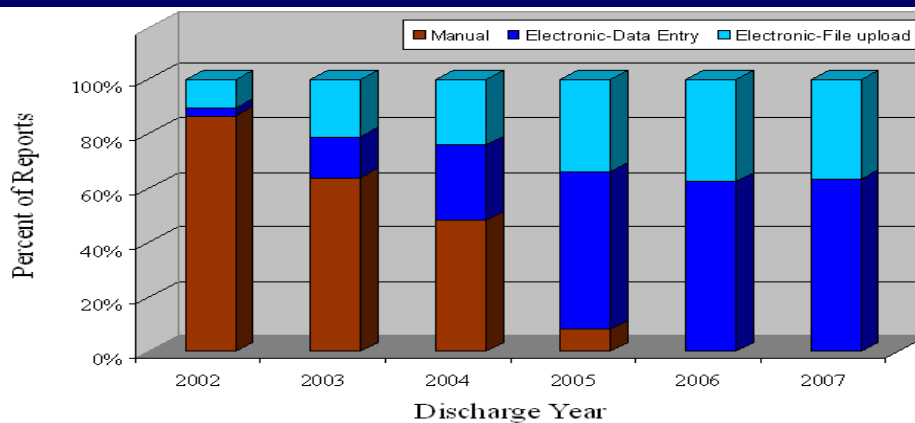


NYS Congenital Malformations Registry 2008 Reports by Source

Routine Hospital Reports	16,508	82.6%
Hospital Discharge Index	1,810	9.1%
Hospital Discharge (SPARCS) Audit	1,524	7.6%
Hospital Site Visit	108	0.5%
Link to National Birth Defects Prevention Study	37	0.2%
Total *	19,987	100%

* Excludes 6,653 duplicate and invalid reports

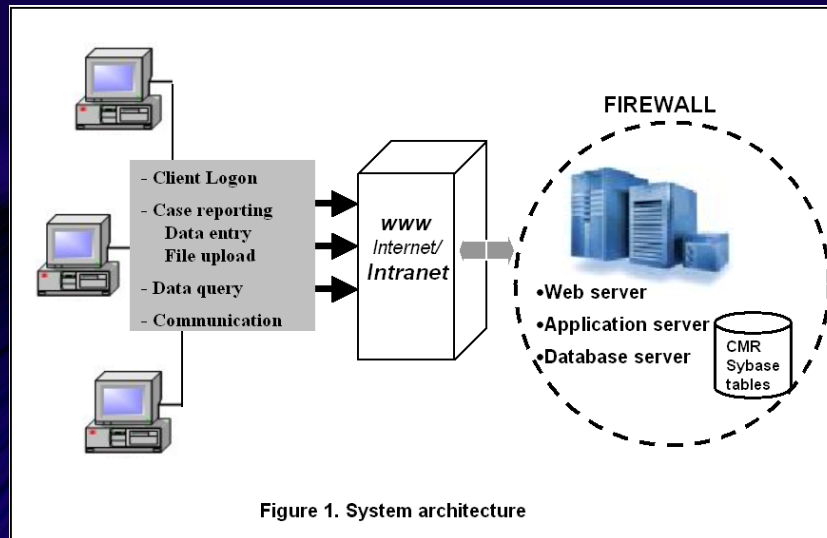
NYS Congenital Malformations Registry *Transition from Manual to Electronic Reporting*



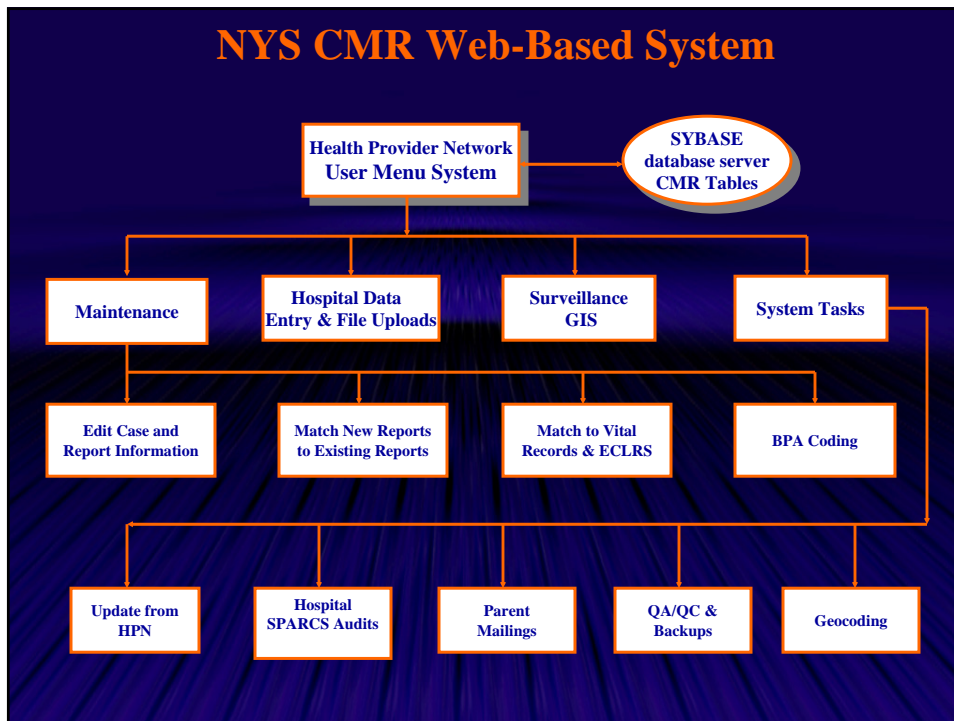
Note: All 163 hospitals submit cases through web-based reporting system as of 01/01/2006

New York State Department of Health

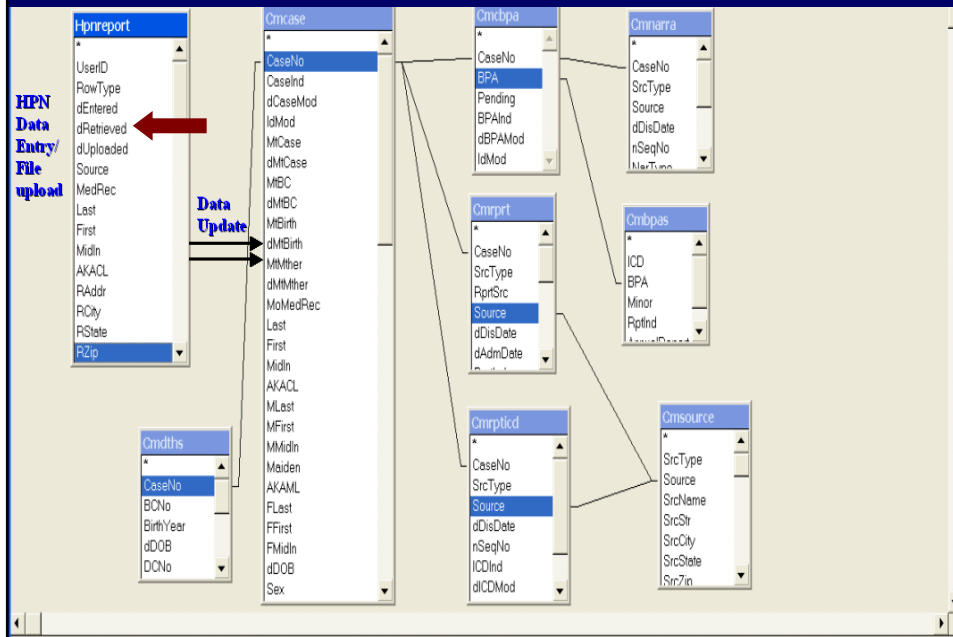
NYS Congenital Malformations Registry Web-based System



NYS CMR Web-Based System



NYS CMR Relational Database - Sybase Tables



New York State Department of Health Health Commerce System

Address: <https://commerce.health.state.ny.us/hpr/> Go

Welcome to HYSDOH HCS Elliot Spitzer, Governor | Richard F. Daines, M.D., Commissioner

Please login to begin using the Health Commerce System

User id:

Password:

Site Policies/Terms of Use

Violation of the security and use agreement (e.g. sharing your account userid and password with someone else) will result in the temporary suspension of your account privileges until required remedial action is taken by executives at your facility.

Repeat offenses may result in the permanent removal of the account.

Contacting the Commerce Accounts Management Unit with someone else's account information will result in the account being disabled due to a security breach.

Important Site Notices

Login Page Update:

How you can just hit return after entering your ID and password

New Features Coming Soon

Access Reset Feature:
Will allow you to access Commerce, anytime, day or night, 24x7.

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CMR Mandatory Access Control

The screenshot shows a web browser window with the URL <https://commerce.health.state.ny.us/hin/cgi-bin/applinks/hinapct/hinapct.cgi>. The page title is "CMR Mandatory Access Control".

At the top, there is a navigation menu with options: File, Edit, View, Favorites, Tools, Help. Below this is a search bar and a list of icons for Back, Forward, Stop, Refresh, Home, Search, Favorites, History, Mail, Print, Edit, Discuss, Research, and Messenger.

The main content area is divided into several sections:

- User ID and Application Search:** Fields for "User ID:" (pkc02) and "Last Name:". A "Select" button is next to the text "a User ID (or last name) and/or Application". Below this is a table with "Application" and "User ID" columns. A blue box on the right says "CMR Staff Grant Access & Permissions".
- Application and User ID Table:**

Application	cehcmr	pkc02	cehcmr	hospital	all	all
User ID	pkc02					
- Permissions:** A list of permissions with buttons for "Delete", "Help", "Change Application Status(Online/Offline)", "View Administrative Access", and "Permission Deleting Application".
- Select Parameters for Adding users to cehcmr - multiple selections are allowed using shift/control keys in these selection windows:**
 - Select hospital:** A list of hospitals including "all -- All Hospital PFI's As A Group", "0306 -- Adirondack Medical Center - Lake Placid Site", "0324 -- Adirondack Medical Center - Saranac Lake Site", "0001 -- Albany Medical Center Hospital", "0002 -- Albany Medical Center South Clinical Campus", "0004 -- Albany Memorial Hospital", and "6304 -- Albany Regional Eye Surgery Center, LLC".
 - User ID-->:** A field containing "pkc02".
 - Permissions:** A list of permissions: "All Permissions For This Application", "Delete Permission For This Application", "Insert Permission For This Application", "Select Permission For This Application", and "Update Permission For This Application".

Mandatory Access Control

CMR Staff Main Menu

Welcome to
New York State's
Congenital Malformations Registry

Select from the tasks below:

- Health Provider Network Reporting System
 - [CMR Handbook](#)
 - [Enter confidential case reports](#)
 - [Upload case reports data](#)
 - [Edit/View unprocessed case reports](#)
 - [View/Search all case reports](#)
 - [View the transaction log](#)
- Cytogenetic Laboratory Reporting System
 - [Enter lab reports](#)
 - [View/Edit / Search lab reports](#)
 - [Add / View/Edit cytotgenetic lab contact information](#)
- [Hospital responses to queries \(16\)](#)
- [View/Edit CMR hospital contact information](#)
- [Contact the CMR](#)
- [CMR Specific Tasks](#) ←

Hospital Staff Main Menu

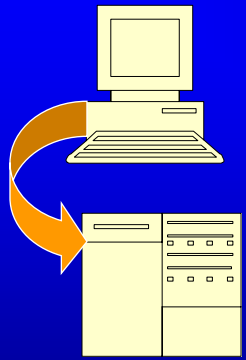
Beth Israel Medical Center (New York)

Welcome to
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Select from the tasks below:

- Health Provider Network Reporting System
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 - [View/Search all case reports](#)
 - [View the transaction log](#)
- [Check outstanding queries from CMR \(2\)](#) ↓
- Generate Report Tables
 - [View number of discharges / reports by discharge year](#)
 - Report card
 - [July 2007 - Dec 2007](#)
 - [Jan 2008 - Jun 2008](#)
 - [July 2008 - Dec 2008 \(available on 04/01/2009\)](#)
 - [View/Edit CMR hospital contact information](#)
- [Contact the CMR](#)

CMR File Uploads



Upload Failed

Error Report

CMR Electronic Reporting Record Layout & Description of Variables

MAKE SURE TO USE FIXED LENGTH NOT VARIABLE LENGTH RECORDS
THERE MUST BE A CARRIAGE RETURN LINE FEED AFTER EACH RECORD (Hex 0D0A)

Variable	Starting Position	Ending Position	Length	Notes
PFI Number	1	4	4	Required
Medical Record Number	5	21	17	Left-aligned
Child's Last Name	22	41	20	Required Left-aligned
First Name	42	51	10	Left-aligned
Middle Initial	52	52	1	
AKA	53	72	20	Left-aligned
Street Address	73	108	36	Left-aligned Should follow US Post Office specifications for abbreviations
City	109	123	15	Left-aligned
State	124	125	2	Should follow US Post Office specifications for abbreviations
Zip Code	126	134	9	Left-aligned Hyphen removed in 9 digit Zip Codes (e.g., 12180-2216 as 121802216)
Date Of Birth	135	142	8	Required Use form yyyymmdd
Birth Status	143	143	1	0=Missing 1=Live 2=Still
Birthweight	144	147	4	Right-aligned In grams
Sex	148	148	1	Required 1=Male 2=Female 3=Under/assigned
Race	149	149	1	0=Missing 1=White 2=Black or African American 3=American Indian/Alaskan Eskimo 4=Asian/Pacific Islander 9=Unknown
Hispanic	150	150	1	0=Missing 1=Yes 2=No
Plurality	151	151	1	0=Unknown 1=Single 2=Twin 3=Triplet Other Specify

View Transaction Log

CMR Test Hospital (Troy)
Transactions Log

Date of Transaction	Type of Transaction	User ID	Infant's Name	Date of Birth	Date of Discharge	Medical Record #	Date Entered or Uploaded
Oct 7 2003 10:22AM	Updated	jlc16	test4, YITZCHAK	09/08/2001	09/18/2001		01/01/1900
Oct 7 2003 10:25AM	Updated	jlc16	test4, YITZCHAK	09/08/2001	09/18/2001		01/01/1900
Oct 7 2003 10:27AM	Updated	jlc16	test4, YITZCHAK	09/08/2001	09/18/2001		01/01/1900
Oct 7 2003 10:31AM	Updated	jlc16	test4, YITZCHAK	09/08/2001	09/18/2001		01/01/1900
Oct 7 2003 11:03AM	Deleted	jlc16	CUKROVANY, JEN	12/08/1967	12/16/1967		01/01/1900
Oct 7 2003 11:04AM	Updated	jlc16	CUKROVANY, JEN	12/08/1967	12/26/1967		01/01/1900
Oct 7 2003 11:07AM	Deleted	jlc16	CUKROVANY, JEN	12/08/1967	12/26/1967		01/01/1900
Oct 7 2003 11:09AM	Deleted	jlc16	CUKROVANY, JEN	12/08/1967	12/26/1967		01/01/1900
Oct 7 2003 11:11AM	Deleted	jlc16	CUKROVANY, JEN	12/08/1967	12/26/1967		01/01/1900
Oct 7 2003 11:15AM	Deleted	jlc16	CUKROVANY, JEN	12/08/1967	12/26/1967		01/01/1900
Oct 7 2003 11:50AM	Deleted	jlc16	CUKROVANY, JEN	11/25/1979	11/30/1979		01/01/1900
Oct 7 2003 11:54AM	Updated	jlc16	CROSS, 0	02/01/1999	02/12/1999		01/01/1900
Oct 21 2003 11:35AM	Updated	lkb01	CROSS, 0	02/01/1999	02/12/1999		01/01/1900
Oct 21 2003 11:39AM	Added	lkb01	SPRAT, JACK	01/02/2003	02/14/2003		10/21/2003
Oct 21 2003 11:40AM	Updated	lkb01	SPRAT, JACK	01/02/2003	02/14/2003		01/01/1900
Nov 20 2003 10:59AM	Added	jlc16	TEST - TEST,	11/02/2003	11/12/2003		11/20/2003
Nov 20 2003 11:00AM	Updated	jlc16	TEST - TEST,	11/02/2003	11/12/2003		01/01/1900
Nov 20 2003 11:01AM	Added	jlc16	JEN-TEST, JEN-TEST	11/04/2003	11/11/2003		11/20/2003

New York State Department of Health Congenital Malformations Registry

[Return To Main Menu](#)

Edit/View Unprocessed Case Reports

PFI Number	Name (City)	New Reports	Number Ready To Update	Incomplete Reports	Number Of Reports	Date Of Last Reports
3058	Albert Einstein College of Medicine (Bronx)	7	6	1	14	02/04/2009
0085	Auburn Memorial Hospital (Auburn)	0	0	1	1	04/10/2008
0746	Bassett Health Care (Cooperstown)	0	1	0	1	02/10/2009
1438	Bellevue Hospital Center (Manhattan)	0	3	0	3	02/10/2009
0848	Bellevue Women's Care Center (Niskayuna)	1	1	6	8	02/11/2009
1439	Beth Israel Medical Center (New York)	0	12	2	14	02/09/2009
1178	Bronx-Lebanon Hosp.-Concourse Div. (Bronx)	0	7	8	15	02/04/2009
1286	Brookdale Hospital Medical Center (Brooklyn)	2	0	0	2	12/12/2008
1288	Brooklyn Hospital (Brooklyn)	6	0	3	9	01/08/2009
9999	CMR Test Hospital (Troy)	21	1	1	23	10/09/2008
0135	Champlain Valley Physicians Hosp (Plattsburg)	0	0	1	1	01/22/2009
0636	Crouse Hospital (Syracuse)	42	0	1	43	02/09/2009
0812	E. J. Noble Hospital (Gouverneur)	0	0	2	2	01/09/2009
1626	Elmhurst Hospital Center (Elmhurst)	0	3	0	3	02/11/2009
0599	Facton-St. Luke's Healthcare - St. Luk (Utica)	1	0	0	1	02/11/2009
0779	Good Samaritan Hospital (Suffern)	0	3	0	3	02/10/2009
1445	Harlem Hospital Center (New York)	0	0	2	2	12/04/2008
0913	Huntington Hospital (Huntington)	0	0	1	1	12/16/2008
1165	Jacobi Hospital Center (Bronx)	0	17	8	25	02/06/2009
1629	Jamaica Hospital (Jamaica)	0	0	5	5	01/30/2009
1301	Kings County Hospital Center (Brooklyn)	1	7	1	9	02/11/2009
1450	Lenox Hill Hospital (New York)	0	2	0	2	02/09/2009
1172	Lincoln Medical & Mental Health Ctr (Bronx)	0	11	0	11	02/04/2009
1302	Long Island College Hospital (BROOKLYN)	0	12	6	18	02/09/2009
1630	Long Island Jewish Medical Center (New Hyde Park)	0	97	25	122	02/05/2009
1304	Lutherman Medical Center (Brooklyn)	0	9	0	9	02/09/2009
1305	Maimonides Medical Center (Brooklyn)	140	0	2	142	02/11/2009

CMR: Edit/View Unprocessed Case Reports - Microsoft Internet Explorer

Address: https://bhnm03.health.state.ny.us/fpn/cgi-bin/applinks/cohcmr/case_edit?sentFrom=hosp

New York State Department of Health Congenital Malformations Registry

[Select Another Hospital](#) [CMR Specific Tasks](#) [Return To Main Menu](#)

CMR Test Hospital (Troy) Unprocessed Case Reports

Date Entered	DOH Date	Infant's Name	Date of Birth	Date of Discharge	Medical Record #	Completed	Ready For Update	Query Sent	Physician Letter
01/01/1900	09/06/2005		01/07/2000	03/18/2000	2789937	Yes			
01/01/1900	09/06/2005		11/06/2000	11/09/2000	4000069663	No			
01/01/1900	09/21/2005		11/06/2000	11/09/2000	4000069663	No			
01/01/1900	09/21/2005		01/07/2000	03/18/2000	2789937	Yes			
01/01/1900	09/21/2005		01/07/2000	03/18/2000	2789937	Yes	No	Yes	
08/27/2003	09/19/2003	CUE_JEN	01/22/2004	01/23/2004	987978	Yes	No		
03/14/2006	03/14/2006	TESTDOC	10/22/2003	10/26/2005	123456	Yes	No		

Edit/View Unprocessed Case Reports

CMR Task: Review/ Edit Unprocessed Case Report Screen

Newborn Screening ID number:

Chromosome Studies:

If yes, Karyotype:

If pending, cytogenic lab: CHROMOSOME ANALYSIS

Parent's Information:

Mother's Last Name:

First Name:

Middle Initial:

Maiden Name:

Date of Birth (mm/dd/yyyy):

Social Security Number:

Phone Number:

Father's Last Name:

First Name:

Middle Initial:

Date of Birth (mm/dd/yyyy):

Social Security Number:

Physician's Information:

Physician's Last Name:

First Name:

Address:

Menu Buttons Available to
CMR Staff on the Edit Screen

CMR INFORMATION REQUEST

<p>PFI Name: 1286 Brookdale Hospital Medical Center</p> <p>Name:</p> <p>DOB:</p> <p>Medical Record #:</p> <p>Discharge Date: 09/25/2006</p>	<p>1st Letter Sent:</p> <p>2nd Letter Sent:</p> <p>Date Called:</p> <p>Date of Response:</p>
--	--

**Hospital
Query**

1. Please specify the Congenital Anomaly listed as unspecified anomaly of aortic valve
All diagnoses listed as 'Anomaly of...'; 'NOS or NEC' must be more specific.

2. Information is incomplete, please specify

3. Diagnosis of is listed as probable/possible. please indicate if verified or ruled out.

4. This chromosome related anomaly was reported
 Please list the results of the chromosome studies/name of cytogenic lab where chromosome studies were performed.
All diagnosis of anomalies listed as a ICD9 code of 758 and 255.2 and 752.7 require chromosome study results to confirm the diagnosis. If this child was not born in your facility and therefore the chromosome information is not available from you institution, please provide the name of the child's pediatrician.

5. ICD Code and Narrative do not match. Which one is correct?

CMR Staff Screen for BPA Coding Malformations

Case and Discharge Information

Case Number = 2006005597

Infant's Name Date of Birth
 Sex: Male Birth Weight: 2833

Narrative Information:

Source Type	Source	Date of Discharge	Nar Seq
H	001464	06/11/2006	
H	001463	08/29/2006	
H	001463	08/29/2006	

New York State Department of Health Congenital Malformations Registry

[Return To Specific Tasks](#)
 [Do Another Search](#)
 [Return To Main Menu](#)

List of ICD, BPA and Narratives

ICD	BPA	N Req	Reportable	Minor	Narratives
55329	756795	N	Y	N	Epigastric hernia
74761	747601	Y	Y	N	Gastrointestinal vessel anomaly
7507	750700	Y	Y	N	Microgastria
7507	750710	Y	Y	N	Megalogastria
75679	756710	Y	Y	N	Gastroschisis

ICD Information:

Source Type	Source	Date of Discharge	M Re	ICD	BPA	N Req	Reportable	Minor
H	001464	06/11/2006						
H	001463	08/29/2006				1		55090
H	001463	08/29/2006				2		75489

BPA Information:

BPA Code	Pending
754820	N

SAS Applications to Monitor Hospital Reporting

New York State Department of Health

Congenital Malformations Registry

[CMR Specific Tasks](#)

[Return To Main Menu](#)

Congenital Malformations Registry

Birth Defects Surveillance in New York State

----- Monitor the Completeness of Case Reporting -----

1. Generate **Report Cards** for reporting hospitals
 2. List the number of discharges/reports for all reporting hospitals by discharge year
 3. List the number of discharges/reports for a selected hospital by discharge year & month
 4. Generate the live birth counts for a selected hospital by birth year & month
 5. List the hospital discharges, live birth and CMR reports by birth year for a selected hospital
 6. Check the completeness of reporting using previous birth years' reports as the baseline --- all hospitals
 7. Check the completeness of reporting using previous birth years' reports as the baseline --- a selected hospital
-
8. List of CMR cases and percent of BC-matches by birth year for all reporting hospitals

[Back to Surveillance Menu](#)

New York State Department of Health Congenital Malformations Registry

CMR Specific Tasks Birth Defects Surveillance in NY Return To Main Menu

Birth Defects Surveillance in New York State

----- Monitor the Completeness of Case Reporting -----

Generate *Report Card* for Reporting Hospitals

Please make the following selections :

1) Select Hospital: (By default all hospitals)

0001: Albany Medical Center Hospital

3068: Albert Einstein College of Medicine

0325: Alice Hyde Memorial Hospital

0482: Amsterdam Memorial Hospital

0116: Arnot Ogden Medical Center

0085: Auburn Memorial Hospital

0739: Aurelia Osborn Fox Memorial Hospital

0746: Bassett Health Care

1438: Bellevue Hospital Center

0848: Bellevue Woman's Hospital

2) Report Monitoring Period - Discharge year & month:

Start Year-Month: 2007 / 07 ----> End Year-Month: 2007 / 12

3) Reference Period - Discharge year & month:

Start Year-Month: 2000 / 07 ----> End Year-Month: 2004 / 12

4) Output Format: HTML PDF RTF

Congenital Malformations Registry

Report Card

0001: Albany Medical Center Hospital

TERM: 07 / 2007 - 12 / 2007

Prepared on: January 15, 2008

Average number of days between discharge date and date of reports sent to CMR for this monitoring period : **22 days**

Category	Monitoring Period (2007)		Baseline Average (2000-2004)	
	Number of Reports	Percent	Number of Reports	Percent
Reports by Discharge Month	Jul	29	24	120.8
	Aug	38	24	158.3
	Sep	29	25	116.0
	Oct	28	27	103.7
	Nov	22	25	88.0
	Dec	27	26	103.8
	Total Reports	173	151	114.6
Reports Deleted	Duplicate Report	24	0	.
	Birth Weight or Sex Effected Code	4	0	.
	Minor without Major Malformation	3	0	.
	Unknown	0	6	.
	Total Deleted	31	6	.
Query Sent	Completed	5	0	.
	Deleted	1	0	.
	Total Queries	6	0	.

*Queries were not sent to hospitals until 2005
 *Reports deleted categories were not established until 2007

New York State Congenital Malformations Registry
Prevalences per 10,000 live births by birth year, sex & race
(Children of New York State residents with selected major malformations)
Birth year = 2001 - 2005
Organ system = No selection
Specific defects = All 45 selected malformations
Prepared on: November 5, 2007

Geographic location	Total children	Total Prevalence	Male	Female	Prevalence Ratio (M/F)	Non-Hispanic White	Non-Hispanic Black	Hispanic	Other & Unknown Race	Mothers Age <35yrs	Mothers Age >=35yrs
ALBANY	294	184.2	256.3	108.9	2.4	184.8	186.6	165.4	186.0	174.3	221.8
ALLEGANY	46	173.8	223.8	115.0	1.9	181.7	0.0	0.0	0.0	171.8	191.6
BRONX	1,930	172.0	225.7	116.3	1.9	183.9	164.3	175.2	170.6	165.4	211.1
BROOME	199	192.5	229.6	152.7	1.5	187.8	223.3	231.7	217.0	189.4	209.9
CATTARAUGUS	97	202.8	253.9	147.8	1.7	208.9	188.7	0.0	170.6	210.0	147.1
CAYUGA	80	190.5	287.6	88.1	3.3	187.9	283.0	0.0	352.9	197.3	153.4
CHAUTAUQUA	177	246.7	312.7	177.3	1.8	242.8	451.6	254.4	192.3	254.3	179.1
CHEMUNG	109	211.8	272.2	149.7	1.8	227.3	104.5	0.0	0.0	186.0	417.4
CHENANGO	62	226.9	296.6	148.2	2.0	230.9	833.3	0.0	0.0	210.9	350.3
CLINTON	63	166.3	199.0	133.1	1.5	163.7	263.2	277.8	204.1	159.4	221.2
COLUMBIA	47	160.7	212.1	105.9	2.0	159.7	256.4	129.0	90.9	157.5	175.8

Converting to a Web-Based System: Resources

- ❖ **Local Area Network (LAN)**
- ❖ **Internet Access & Browser** (Netscape, Explorer)
- ❖ **Secure web site (https)**
- ❖ **Server (s)**
 - Application Development
 - Relational Database (Oracle, Sybase etc.)
 - Web Communication
- ❖ **Software (Java, JavaScript, SAS Intrnet)**
- ❖ **IT / IS support (system maintenance / backups)**



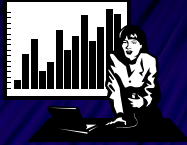
Converting to a Web-Based System Staff

❖ **Dedicated Programmer(s)** (2 to 3 years minimum)



MS computer science (BS with experience)
Database design
Web application development
Programming (JavaScript, HTML, PERL, SAS)

❖ **Reporting Coordinator**



Develop menus & screens
Documentation & instructions
Promote / Implement / Pilot Test
Monitor reporting / Troubleshoot
Contact person (excellent people skills)

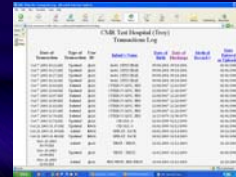
Converting to a Web-Based System Tips & Recommendations

- **Start by meeting with your IS/IT Department staff**
- **Keep it simple at first then expand - data entry**
 - required fields with edit checks at the source
 - good matching algorithm for new case reports
 - maintain a report file with “unprocessed” cases
- **Pilot test with 2 - 3 hospitals**
- **Conduct regional meetings to “sell” the new system**
 - solicit ideas for new applications and/or improvements
- **Allow hospitals to edit “unprocessed” case reports**

Converting to a Web-Based System Tips & Recommendations

- **Transaction log is important**

- Identify reporting source
- Code reasons for deleting cases



Record	Date	User	Action	Status
10000001	2008-01-01	ADMIN	CREATE	OK
10000002	2008-01-01	ADMIN	CREATE	OK
10000003	2008-01-01	ADMIN	CREATE	OK
10000004	2008-01-01	ADMIN	CREATE	OK
10000005	2008-01-01	ADMIN	CREATE	OK
10000006	2008-01-01	ADMIN	CREATE	OK
10000007	2008-01-01	ADMIN	CREATE	OK
10000008	2008-01-01	ADMIN	CREATE	OK
10000009	2008-01-01	ADMIN	CREATE	OK
10000010	2008-01-01	ADMIN	CREATE	OK
10000011	2008-01-01	ADMIN	CREATE	OK
10000012	2008-01-01	ADMIN	CREATE	OK
10000013	2008-01-01	ADMIN	CREATE	OK
10000014	2008-01-01	ADMIN	CREATE	OK
10000015	2008-01-01	ADMIN	CREATE	OK
10000016	2008-01-01	ADMIN	CREATE	OK
10000017	2008-01-01	ADMIN	CREATE	OK
10000018	2008-01-01	ADMIN	CREATE	OK
10000019	2008-01-01	ADMIN	CREATE	OK
10000020	2008-01-01	ADMIN	CREATE	OK
10000021	2008-01-01	ADMIN	CREATE	OK
10000022	2008-01-01	ADMIN	CREATE	OK
10000023	2008-01-01	ADMIN	CREATE	OK
10000024	2008-01-01	ADMIN	CREATE	OK
10000025	2008-01-01	ADMIN	CREATE	OK
10000026	2008-01-01	ADMIN	CREATE	OK
10000027	2008-01-01	ADMIN	CREATE	OK
10000028	2008-01-01	ADMIN	CREATE	OK
10000029	2008-01-01	ADMIN	CREATE	OK
10000030	2008-01-01	ADMIN	CREATE	OK
10000031	2008-01-01	ADMIN	CREATE	OK
10000032	2008-01-01	ADMIN	CREATE	OK
10000033	2008-01-01	ADMIN	CREATE	OK
10000034	2008-01-01	ADMIN	CREATE	OK
10000035	2008-01-01	ADMIN	CREATE	OK
10000036	2008-01-01	ADMIN	CREATE	OK
10000037	2008-01-01	ADMIN	CREATE	OK
10000038	2008-01-01	ADMIN	CREATE	OK
10000039	2008-01-01	ADMIN	CREATE	OK
10000040	2008-01-01	ADMIN	CREATE	OK
10000041	2008-01-01	ADMIN	CREATE	OK
10000042	2008-01-01	ADMIN	CREATE	OK
10000043	2008-01-01	ADMIN	CREATE	OK
10000044	2008-01-01	ADMIN	CREATE	OK
10000045	2008-01-01	ADMIN	CREATE	OK
10000046	2008-01-01	ADMIN	CREATE	OK
10000047	2008-01-01	ADMIN	CREATE	OK
10000048	2008-01-01	ADMIN	CREATE	OK
10000049	2008-01-01	ADMIN	CREATE	OK
10000050	2008-01-01	ADMIN	CREATE	OK

- **File uploads for larger hospitals**

- Flag errors by type and record number and reject files with any errors
- Check for gaps in reporting
- Expect duplicates
- Allow for hospital staff edits after upload

- **Frequent backups with offsite storage**

Converting to a Web-Based System Tips & Recommendations

- **Routine data QA/QC programs and procedures**

- **Provide clear instructions and good documentation**

- Electronic handbook
- Reportable malformations

- **Hospital communication and feedback**

- Maintain a hospital contact database
- Notification procedures for interruptions, updates and technical problems
- Hospital “Report Cards”

- **Contact other programs for advice/assistance**



Striving for
Healthy
Births



New York State Congenital Malformations Registry
New York State Department of Health
Center for Environmental Health

Improving the Quality
of CMR Data

Congenital Malformations Registry *Timeliness of Case reporting*

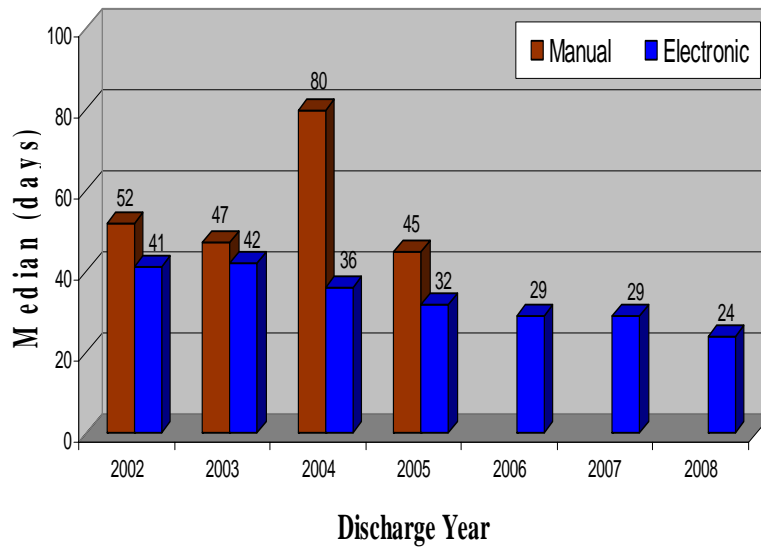


Table 2. The number of cases and the percent of unspecified codes for the selected birth defect category by case reporting systems, paper-based (manual) and web-based (HPN) reporting

Selected birth defect category	BPA codes (unspecified BPA codes)	Total	Cases with unspecified codes		% of cases with unspecified codes by reporting system		
			N	%	Manual	HPN	p-value
Other specified anomalies of heart	746.8, 746.9 (746.880, 746.900, 746.990)	1,228	329	26.8	32.9	17.6	<0.001
Other specified anomalies of pulmonary artery	747.3 (747.380, 747.390)	2,179	68	3.1	3.7	2.5	<0.05
Other obstructive defects of renal pelvis/ureter	753.2 (753.290)	4,299	353	8.2	12.7	3.5	<0.001
Total selected cases		7,706	750	9.7			

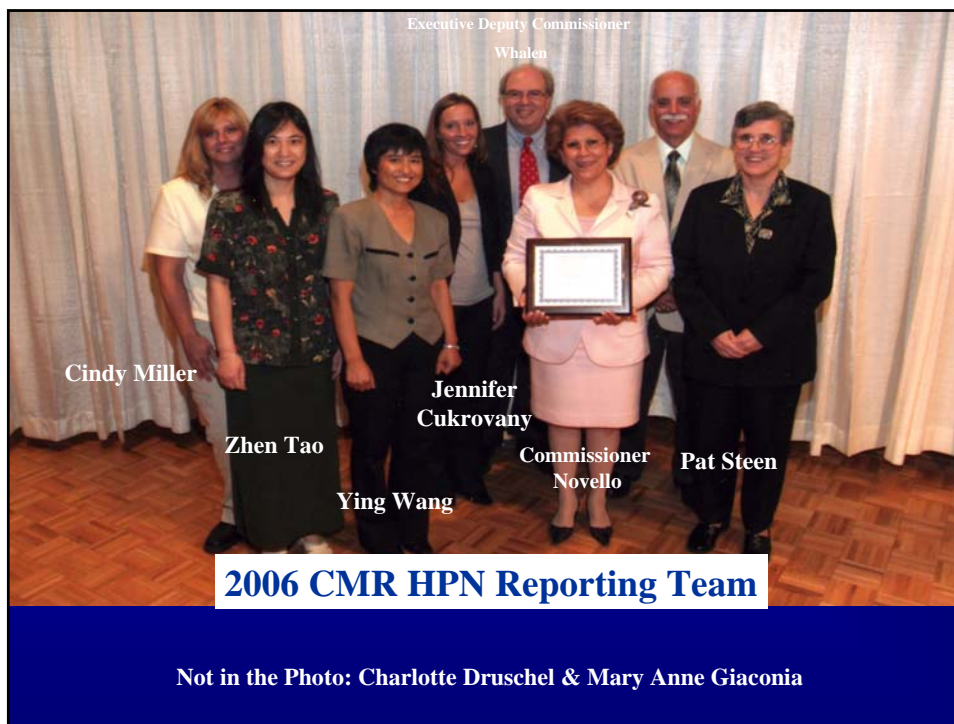
**CMR Prevalence
Compared to
National
Estimates**

Section V - Table 1
Prevalence* of selected major birth defects in New York State
(Birth years: 2003-2005)

Birth defect Category	New York City	Upstate NY	New York State	NBDPN 1999-2001	95% CI Range
Central nervous system defects					
Anencephalus	0.3	0.5	0.4	2.5	2.3-2.7
Spina bifida without anencephalus	1.6	2.2	1.9	3.7	3.4-3.9
Encephalocele	0.4	0.6	0.5	0.9	0.8-1.0
Eye defects					
Anophthalmia/ microphthalmia	0.6	0.9	0.8	2.1	1.9-2.3
Cardiovascular defects					
Common truncus	1.0	0.4	0.7	0.8	0.7-0.9
Transposition of great arteries	3.6	4.7	4.2	4.7	4.5-5.0
Tetralogy of Fallot	4.8	4.9	4.9	3.9	3.8-4.2
Endocardial cushion defect	2.6	3.1	2.8	4.4	4.1-4.6
Hypoplastic left heart syndrome	2.1	2.8	2.5	2.4	2.2-2.6
Orofacial defects					
Cleft palate without cleft lip	4.2	6.5	5.4	6.4	6.1-6.7
Cleft lip with and without cleft palate	5.4	8.4	7.0	10.5	10.1-10.9
Gastrointestinal defects					
Esophageal atresia/ tracheoesophageal fistula	2.7	2.0	2.4	2.4	2.2-2.6
Rectal and large intestinal atresia/stenosis	4.4	4.7	4.6	4.8	4.5-5.1
Musculoskeletal defects					
Reduction deformity, upper limbs	1.4	2.1	1.8	3.8	3.5-4.0
Reduction deformity, lower limbs	0.7	1.0	0.9	1.9	1.7-2.1
Gastrochisis	1.4	2.5	2.0	3.7	3.5-4.0
Omphalocele	1.1	1.4	1.3	2.1	1.9-2.3
Diaphragmatic hernia	1.8	2.5	2.2	2.9	2.7-3.1
Chromosomal defects					
Trisomy 13	0.9	0.9	0.9	1.3	1.2-1.5
Down syndrome(trisomy 21)	11.0	13.6	12.4	13.7	13.2-14.1
Trisomy 18	0.9	1.1	1.0	2.4	2.2-2.6

* - Prevalence (number of defects per 10,000 live births)

Bold prevalences are within the range of the 11 active registries
Boxed prevalences are equal to or greater than the lower limit of the 95% CI range



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