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**



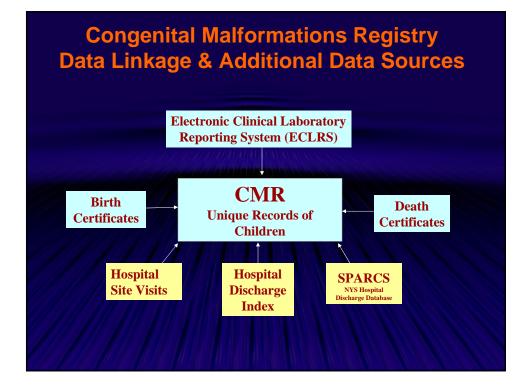
Electronic Card File 1980's "Technology" Statewide - approximately 250,000 to 300,000 births annually

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

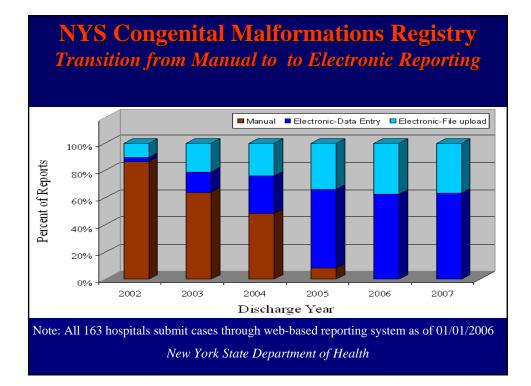
Cases can be diagnosed with 20+ major malformations

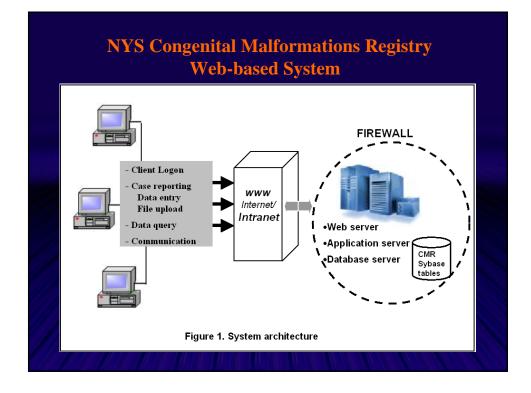
Cases can be reported multiple times from one or more hospitals & by physicians up to the age of 2

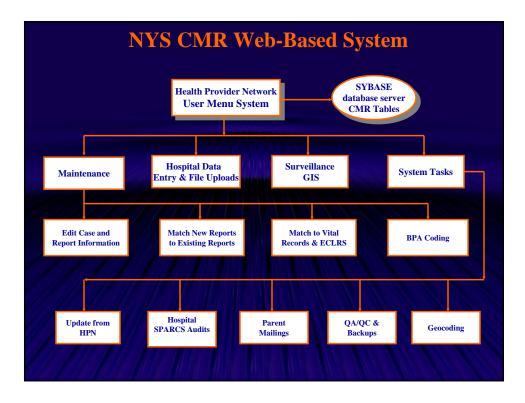
Reports from all sources are maintained and linked with a unique case number

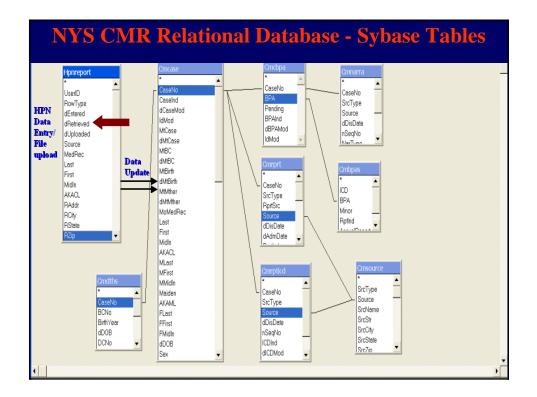


<b>Routine Hospital Reports</b>	16,508	82.6%
Hospital Discharge Index	1,810	9.1%
Hospital Discharge (SPARCS) Audit	1,524	7.6%
Hospital Site Visit	108	0.5%
Link to National Birth Defects Prevention Study	37	0.2%
Total *	19,987	100%











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G . Back	Forward	Stop	2 Refresh	Home	Search	Favorites	History	Mail	Print	Edit	-	Discuss	Research	n Messenger
kddress 🗟 http	s://commerc	e.health.stat	e.ny.us/hin/o	gi-bin/applink	s/hinapcf/hina	pcf.cgi							*	🔁 Go Links "
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Mandatory Access Control						
CMR Staff Main Menu	<u>Hospital Staff Main Menu</u>					
Welcome to	Beth Israel Medical Center (New York)					
New York State's						
Congenital Malformations Registry	Welcome to					
Congenium manorinadons reegistry	New York State's					
Select from the tasks below:	Congenital Malformations Registry					
Health Provider Network Reporting System	Select from the tasks below:					
<ul> <li><u>CMR Handbook</u></li> <li>Enter confidential case reports</li> </ul>	Health Provider Network Reporting System					
o Upload case reports data	o CMR Handbook					
• Edit/View unprocessed case reports	<ul> <li>Enter confidential case reports</li> <li>Upload case reports data</li> </ul>					
o <u>View/Search</u> all case reports	<ul> <li>Optional case reports data</li> <li>Edit/View unprocessed case reports</li> </ul>					
<ul> <li><u>View the transaction log</u></li> </ul>	o View/Search all case reports					
Cytogenetic Laboratory Reporting System	<ul> <li>View the transaction log</li> </ul>					
<ul> <li>Cytogeneric Laboratory Reporting System</li> <li>Enter lab reports</li> </ul>	Check outstanding queries from CMR (2)					
<ul> <li><u>View/Edit</u> / <u>Search</u> lab reports</li> </ul>	• <u>Check outstanding queries from Civity</u> (2)					
<ul> <li><u>Add</u> / <u>View/Edit</u> cytogenetic lab contact information</li> </ul>	Generate Report Tables					
<ul> <li>Hospital responses to queries (16)</li> </ul>	<ul> <li>View number of discharges / reports by discharge year</li> <li>Report card</li> </ul>					
• riospital responses to queries (16)	July 2007 - Dec 2007					
View/Edit CMR hospital contact information	Jan 2008 - Jun 2008					
	<ul> <li>July 2008 - Dec 2008 (available on 04/01/2009)</li> </ul>					
<u>Contact the CMR</u>	o View/Edit CMR hospital contact information					
<u>CMR Specific Tasks</u>	o Contact the CMR					

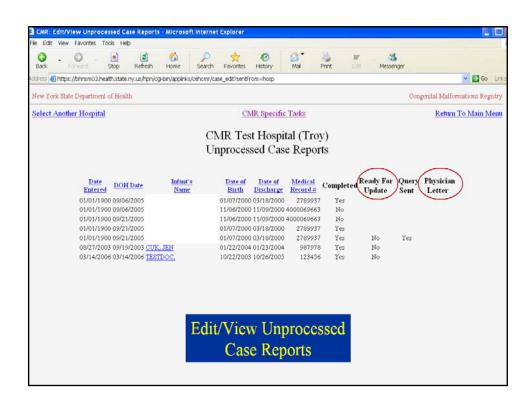
New York State Department of Health       Screen 1       Congenital Malformations Registry         Help Entering Date       Return to Main Menu         Routine Current Case Report         Child's Information:         PFI Number:         DOH Date:         Medical Record Number:         Child's Last Name:         Pri Name:         Middle Initial:         If child is been indentified by another name, enter the name:         State:         State:         Zip Code:         Date of Birth (maidatypy);         Birth Status:         With Status:         Birth Status:         With Status:         Birth Status:         With Status:         Birth Status:         Birth Status:         Birth Status:         Birth Status:         Race:         Machine Birth, maidatypy);         Birth Status:         Birth Status:         Birth Status:         Birth Status:         Birth Status:         Birth Status:         Race:         Race:         Mathema Date of Birth, maidatypy);         Birth Status:         Birth Status: <th>Address 🍓 https://commerce.health.state.ny.us/hpn/cgi-bin/applink</th> <th>Hognital Data Entry</th> <th>💌 🛃 Go 🛛 Links</th>	Address 🍓 https://commerce.health.state.ny.us/hpn/cgi-bin/applink	Hognital Data Entry	💌 🛃 Go 🛛 Links
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Child's Information: PFI Number: DOH Date: DH D	Help Entering Data		Return to Main Menu
<ul> <li>PFI Number:</li> <li>PFI Number:</li> <li>OH Date:</li> <li>DOH Date:</li> <li>PFI No: <i>A Required Field for Hospitals</i> This is your permanent facility identification number. It is the first four digits of SPARCS hospital ID number.</li> <li>Pfi No: <i>A Required Field for Hospitals</i> This is your permanent facility identification number. It is the first four digits of SPARCS hospital ID number.</li> <li>Pfi No: <i>A Required Field for Hospitals</i> This is your permanent facility identification number. It is the first four digits of SPARCS hospital ID number.</li> <li>Prist Name:</li> <li>Niddle Initial:</li> <li>I' child has been indentified by another name, enter the name:</li> <li>Redical Record Number: The number assigned by the hospital. This is critical for follow-up. It should not be more than 10 digits. Do not include dashes, spaces or preceding zeros.</li> <li>Child's Information</li> <li>Child's Name:</li> <li>Last name: <i>A Required Field</i> The child's last name as listed on the birth certificate. The last name may be hyphenated. Do not use special characters such as apostrophes or periods.</li> <li>First name: Do not use "male/female child", B/G / B/B, or mother's first name. Please fease blank if child is not named.</li> <li>Mil: The child's middle initial.</li> <li>4. AKA: Use this field for name(s) different from the child's last name listed above. If the child has been identified by another name, for example the mother's maiden name, enter the name. The name may be hyphenated. Do not use special characters such as apostrophes or periods.</li> <li>5. Address: The child's middle initial.</li> <li>4. AKA: Use this field for name(s) different from the child's last name listed above. If the child has been identified by another name, for example the mother's maiden name, enter the name. The name may be hyphenated. Do not use special characters such as apostrophes or periods.</li> <li>5. Address: The child's current street address, city, state, and zip code. Correct spelling of the street, townicity an</li></ul>		Routine Current Case Rep	ort
DOH Date:       Image: State:         Medical Record Number:       Image: State:         Child's Last Name:       Image: State:         In Address:       Image: State:         City:       Image: State:         State:       Image: State:         Date of Dirk (um/d49yyyy):       Image: State:         Born at this facility:       Image: State:         If not on at this facility:       Image: State:         State:       Image: State:         Date of Dirk (um/d49yyyy):       Image: State:         State:       Image: State:         Image:       Image: State:         Image:       Image: State:         State:       Image: State:         Birth Status:       Image: State:         State:       Image: State:         Image:       Image: State:         Image:       Image: State:         State:	Child's Information:		
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Audit Record Number:       Identification number: It is the first four digits of SPARCS hospital ID number.         First Name:       Identification number: It is the first four digits of SPARCS hospital ID number.         First Name:       Identification number. It is the first four digits of SPARCS hospital ID number.         Middle Initial:       If child has been indentified by another name, enter the name:         Middle Initial:       If child has been indentified by another name, enter the name:         Street Address:       Image: Image		1 DEI No: A Required Field	
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<ul> <li>Middle Initial:</li> <li>If child has been indeutified by another name, euter the name:</li> <li>Street Address:</li> <li>City:</li> <li>State:</li> <li>Zip Code:</li> <li>Date of Birth (uni/ddyyyy):</li> <li>We have indeutified by another name, euter the name:</li> <li>Sex:</li> <li>Child's Information</li> <li>Child's Name:</li> <li>Last name: A Required Field The child's last name as listed on the birth certificate. The last name may be hyphenated. Do not use special characters such as apostrophes or periods.</li> <li>First name: Do not use 'male/female child', B/G / B/B, or mother's first name. Please leave blank if child is not named.</li> <li>M.L: The child's middle initial.</li> <li>AKA: Use this field for name(s) different from the child's last name listed above. If the child has been identified by another name, for example the mother's maiden name, enter the name. The name may be hyphenated. Do not use special characters such as apostrophes or periods.</li> <li>AKA: Use this field for name(s) different from the child's last name listed above. If the child has been identified by another name, for example the mother's maiden name. The name may be hyphenated. Do not use special characters such as apostrophes or periods.</li> <li>Address: The child's current street address, city, state, and zip code. Correct spelling of the street, town/city and an accurate zip code are important for computerized geocoding.</li> </ul>	Child's Last Name:	Please fill this in since it id	entifies your hospital for CMR data entry. There is a list
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Nate:       name. Please leave blank if child is not named.         Plurality:          Plurality:          Bom at this facility:          Bom at this facility:          Date of Discharge (mm/ddypyy):          Deceased:          Date of Death (mm/ddypyy):          Date of Death (mm/ddypyy):	Sex: 👻	such as apostrophes	or periods.
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Date of Death (mm/dd/yyyy);	Deceased:		
	Date of Death (mg/dd/mm)		

Diagnostic Information:	Hospital Data	Ent	ry	List of Reportable ICD	Codes
ICD Code Narrative	(Screen 2	2)		1	
	CMR: L	ist of Rep	ortable Anon	nalies - Microsoft Internet Explorer	
	New York	: State Dep	partment of He	alth Congenital Malformations R	egistry
			List o	of Reportable Anomalies	
	ICD N Code R	arrative equired	Reportable	Description	
	189.0	Yes	Y	Wilm's tumor (nephroblastoma) only is reportable	
	190.5	No	¥	Retinoblastoma	
Newborn Screening ID number:	191.0	No		Central nervous system neoplasm, cerebrum	
Chromosome Studies:	191.1	No		Central nervous system neoplasm, frontal lobe	
If yes, Karyotype:	191.2	No		Central nervous system neoplasm, temporal lobe	
If pending, Cytogenic Lab:	191.3	No		Central nervous system neoplasm, parietal lobe	
	191.4	No		Central nervous system neoplasm, occipital lobe	
Parent's Information:	191.5	No		Central nervous system neoplasm, ventricles	
	191.6	No		Central nervous system neoplasm, cerebellum nos	
Mother's Last Name:	191.7	Yes		Central nervous system neoplasm, brain stem. Central nervous system neoplasm, other parts of the brain (specify area)	
First Name:	191.0	Yes		Central nervous system neoplasm, brain unspecified (try not to use)	
Middle Initial:	194.0	Yes		Neuroblastoma only is reportable	
Maiden Name:	208.9	No		Leukenia, conzenital	
Date of Birth (nm/dd/yyyy): Social Security Number:	228.00	Yes	N N	Hemangiona - skin> 4* diameter (m) Hemangiona, of unspecified site (m) Noncavemous, single, small hemangiona (less than 4* diameter)	
Phone Number:	228.02	Yes		Hemangioma, intracranial structures (specify region if possible)	
radier's Last Pointe:	228.03	No		Hemangioma, retina	
First Name:	228.04	Yes		Hemangioma, intra abdominal structures (specify structure)	
Middle Initial:	228.09	Yes		Hemangioma, of other sites (specify site) Cystic Hystroma	
Date of Birth (mm/dd/yyyy):	220.1	169		Lynphangiona, any site (specify site)	
	237.70	No		Neurofibromatosis, unspecified	
Social Security Number:	237.71	No		Neurofibromatosis type I Von Recklinghsusen's disease	
Primary Physician's Information:	237.72	No		Acoustic neucofibromatosis Neucofibromatosis type II	
Physician's Last Name: First Name: Address:	238.8	Yes	Y Y Y	Terstons, shoknen Terstons, bask and face Terstons, scale specified sites (please specify site) Terstons, scale: cocycraged	

	Rec		Electronic it & Desci		ing f Variables
CMR File Uploads		RRIAGE RET	URN LINE H		BLE LENGTH RECORDS ER EACH RECORD (Hex: ØDØA)
	Variable	Starting Position	Ending Position	Length	Notes
	PFI Number	1	4	4	
	Medical Record Number	5	21	17	
	Child's Last Name	22	41	20	Left-aligned
	First Name	42	51	10	Left-aligned
	Middle Initial	52	52	1	
	AKA	53	72	20	
	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 yyymmdd
	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=Undesignated
Upload Failed	Race	149	149	1	0=Missing 1=White 2=Black or African American 3=American Indian/Alaskan Eskimo 4=Asian/Pacific Islander 9=Unknown
Error Report	Hispanic	150	150	1	0=Missing 1=Yes 2=No
	Plurality	151	151	1	0=Unknown 1=Single 2=Twin 3=Triplet Other Specify

https://commerce.	health.state.ny.us	/hpn/cgi-bin/applinks/ce	honr/trank					Y 🔁 Go Li
-				CMR Test Hospital	l (Troy)			
				Transactions L	og			
Da	te of action	Type of Transaction	User ID	Infant's Name	<u>Date of</u> <u>Birth</u>	<u>Date of</u> Discharge	Medical Record #	<u>Date</u> Entered or Uploaded
Oct 7 200	3 10:22AM	Updated	jlc16	test4, YTTZCHAK	09/08/2001	09/18/2001		01/01/1900
Oct 7 200	3 10:25AM	Updated	jlc16	test4, YTTZCHAK	09/08/2001	09/18/2001		01/01/1900
Oct 7 200	3 10:27AM	Updated	jlc16	test4, YTTZCHAK	09/08/2001	09/18/2001		01/01/1900
Oct 7 200	3 10:31AM	Updated	jlc16	test4, YTTZCHAK	09/08/2001	09/18/2001		01/01/1900
Oct 7 200	3 11:03AM	Deleted	jlc16	CUKROVANY, JEN	12/08/1967	12/16/1967		01/01/1900
Oct 7 200	3 11:04AM	Updated	jlc16	CUKROVANY, JEN	12/08/1967	12/26/1967		01/01/1900
Oct 7 200	3 11:07AM	Deleted	jlc16	CUKROVANY, JEN	12/08/1967	12/26/1967		01/01/1900
Oct 7 200	3 11:09AM	Deleted	jlc16	CUKROVANY, JEN	12/08/1967	12/26/1967		01/01/1900
Oct 7 200	3 11:11AM	Deleted	jlc16	CUKROVANY, JEN	12/08/1967	12/26/1967		01/01/1900
Oct 7 200	3 11:15AM	Deleted	jlc16	CUKROVANY, JEN	12/08/1967	12/26/1967		01/01/1900
Oct 7 200	3 11:50AM	Deleted	jlc16	CUKROVANY, JEN	11/25/1979	11/30/1979		01/01/1900
Oct 7 200	3 11:54AM	Updated	jlc16	CROSS, 0	02/01/1999	02/12/1999		01/01/1900
Oct 21 20	03 11:35AM	Updated	ikb01	CROSS, 0	02/01/1999	02/12/1999		01/01/1900
Oct 21 20	)3 11:39AM	Added	lkb01	SPRAT, JACK	01/02/2003	02/14/2003		10/21/2003
Oct 21 200	3 11:40AM	Updated	lkb01	SPRAT, JACK	01/02/2003	02/14/2003		01/01/1900
	0 2003 9AM	Added	jlc16	TEST - TEST,	11/02/2003	11/12/2003		11/20/2003
	0 2003 0AM	Updated	jlc16	TEST - TEST,	11/02/2003	11/12/2003		01/01/1900
	2003 1AM	Added	jlc16	JEN-TEST, JEN-TEST	11/04/2003	11/11/2003		11/20/2003

rk State Depa	rtment of Health				Conge	nital Malformations Regist
						<u>Return To Main Mer</u>
	Edit/View Unp	rocesse	d Case Re	ports		
PFI Number	Name (City)	New Reports	Number Ready To Update	Incomplete Reports		f 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 Woman'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	Faxton-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)	Ô	Û	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	Lutheran Medical Center (Brooklyn)	0	9	0	9	02/09/2009
1305	Maimonides Medical Center (Brooklyn)	140	0	2	142	02/11/2009
0010	A.C	0	0	0	0	000000



## CMR Task: Review/ Edit Unprocessed Case Report Screen

Newborn Screening ID number: Chromosome Studies:	
If yes, Karyotype:	
If pending, cytogenic lab: CHROMOS	DNE 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 (nm/dd/yyyy):	
Social Security Number:	Menu Buttons Available to
Physician's Information:	CMR Staff on the Edit Screen
Physician's Last Name:	
First Name:	
Address:	

PFUName: 1286 Brookdale Hospital Medical Center Name:	1st Letter Sent: 2nd Letter Sent:	Hospita
DOB	Date Called:	
Medical Record #:	Date of Response:	Query
Discharge Date: 09/25/2006		Query
✓1. Please specify the Congenital Anomaly listed as U	uspecified anomaly of aor	ic valve
I. Please specify the Congenital Anomaly listed as All diagnoses listed as 'Anomaly of', 'NOS or NI		ie valve
All diagnoses listed as Parolitary of, 1405 of 14	Sc. must be more specific.	
2 Information is incomplete, please specify		
	(m)	
	-	
- CE-SS		
3. Diagnosis of	is listed as probable/poss	ible: please
3. Diagnosis of indicate if verified or ruled out.	is listed as probable/poss	ible; please
	is listed as probable/poss	ible; please
indicate if verified or ruled out.		ible; please
indicate if verified or ruled out. <ul> <li>4. This chromosome related anomaly was reported.</li> <li>Please list the results of the chromosome studies/n</li> </ul>		ible; please
indicate if verified or ruled out. 4. This chromosome related anomaly was reported. Please list the results of the chromosome studies/n chromosome studies were performed.	ame of cytogenic lab where	ible; please
indicate if verified or ruled out. 4. This chromosome related anomaly was reported. Please list the results of the chromosome studies/n chromosome studies were performed. All diagnosis of anomalies listed as a ICD9 code of	ame of cytogenic lab where of 758 and 255.2 and 752.7	ible, please
indicate if verified or ruled out.  4. This chromosome related anomaly was reported. Please list the results of the chromosome studies/n chromosome studies were performed.	ame of cytogenic lab where of 758 and 255.2 and 752.7 agnosis. If this child was not	ible, please
indicate if verified or ruled out.  4. This chromosome related anomaly was reported. Please list the results of the chromosome studies/m chromosome studies were performed. All diagnosis of anomalies listed as a ICD9 code of require chromosome study results to confirm the di	ame of cytogenic lab where of 758 and 255.2 and 752.7 agnosis. If this child was not information is not available	ible, please
<ul> <li>indicate if verified or ruled out.</li> <li>4. This chromosome related anomaly was reported. [ Please list the results of the chromosome studies/n chromosome studies were performed.</li> <li>All diagnosis of anomalies listed as a ICD9 code of require chromosome study results to confirm the diborn in your facility and therefore the chromosome from you institution, please provide the name of the first study o</li></ul>	ame of cytogenic lab where of 758 and 255.2 and 752.7 agnosis. If this child was not information is not available e child's pediatrician.	ible: please
indicate if verified or ruled out. 4. This chromosome related anomaly was reported. Please list the results of the chromosome studies/n chromosome studies were performed. All diagnosis of anomalies listed as a ICD9 code of require chromosome study results to confirm the di- born in your facility and therefore the chromosome	ame of cytogenic lab where of 758 and 255.2 and 752.7 agnosis. If this child was not information is not available e child's pediatrician.	ible: please

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🕫 🔕 https://commerce.h	ealth.state.ny.us/doh3/applinks/cehcmr/cmrInfoRequest?sentFrom=mail8	queryInd=U&pfi=1158&caseEnter=Oct%20%206%202005%20%208:31:11 💌 🔁 Go 🛛 🛛
	CMR INFORMAT	ION REQUEST
	PFI/Name: 1158	1st Letter Sent: 10/06/2005
	Name	2nd Letter Sent:
	DOB:	Date Called:
	Medical Record #:	Date of Response:
	Discharge Date:	
		ly listed as UNSPECIFIED ANOMALY OF AORTIC VALVE ; 'NOS or NEC" must be more specific.
	Response:	
	aortic valve stenosis	×
Send Response	<u>Return To Main M</u>	Hospital Query

G · ⊙ · 🖄 🖄 🔎 🤸 🌒 🕫 😓 · 📙	<u>1000000 10 10000</u> – 6 ×
CMR Specific Tasks	
1	Menu Options Available to CMR Staff
<u>Birth Defects Surveillance in New York State</u>	

					Ca	se			<b>charge Inform</b> ber = 2006005597	ation		
Infant':	s Name						Date o	f Biı	th			
Sex: M	ale						Birth V	Weig	ht:2833			
Narrati	ve Infor	mation:		abnac	odine - A	licros	oft Interne	t Exolo	rer 🔳 🗖			
бош се Туре	Source	Date of Discharge	Nai						ongenital Malformations Registry		1	
н	001464	06/11/2006			To Spe	cific	D	o Ano				
н	001463	08/29/2006		Tasks		Search Menu						
н	001463	08/29/2006			List	of I	CD, B	PA a	and Narratives		j	
				ICD	BPA	N	Rprtable	Mino	r Narratives			
				55329	756795		Y	N	Epigastric hernia	в	PA Inf	format
	6				747601		Y	N	Gastrointestinal vessel anomaly		BPA	ormat
	formati		_		750700		Y	И	Microgastria			Pendi
Source	Source	Date of	M		750710 756710		Y Y	N	Megalogastria Gastroschisis		Code	
Туре	Source	Discharge	Re	13679	736710	1	1	14	GIRT OPCHIERE	75	54820	Ν
н	001464	06/11/2006										
H	001463	08/29/2006				1	55090					

	Congenital Malformations Registry
MR Specific Tasks	Return To Main Ment
Congenital Malformations Registr	У
Birth Defects Surveillance in New York	x State
Monitor the Completeness of Case Rep	orting
1. Generate <i>Report Cards</i> for reporting hospitals	
2. List the number of discharges/reports for all reporting hospitals by discharge y	'ear
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 sele	ected 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
	birth year for all reporting hospitals

w York State Department of Health		Congenital Malformations Registry
IR Specific Tasks	Birth Defects Surveillance in NY	Return To Main Men
	Birth Defects Surveillance in New York State	
	Monitor the Completeness of Case Reporting	
	Generate <i>Report Card</i> for Reporting Hospitals	
Please make the followin	ng selections :	
1)Select Hospital:(By default	all hospitals)	
0001: Albany Medical Center Ho 3068: Albert Einstein Gollege of 0325: Alice Hydre Memorial Hoss 0482: Amsterdam Memorial Hoss 0116: Arnot Ogden Medical Cent 0085: Auburn Memorial Hospital 0739: Aurelia Osborn Fox Memo 0746: Bassett Health Care 1438: Bellevue Hospital Center 0848: Bellevue Woman's Hospit	Medicine — pital pital ter rial Hospital	
2) Report Monitoring Period	- Discharge year & month:	
S	tart Year-Month: 2007 🗸 07 🗸> End Year-Month: 2007 🗸 12 🗸	
3) Reference Period - Discha	rge year & month:	
s	itart Year-Month: 2000 💌 07 💌> End Year-Month: 2004 💌 12 💌	1

	TERM: 07 / 2	lical Center Hospital 2007 - 12 / 2007 January 15, 2008		$\frown$
Average number of days bet	ween discharge date and date of 1			22 days
	Category	Monitoring Period (2007) Number of Reports	Baseline Average (2000-2004) 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	1. A. A.
	Minor without Major Malformation	3	0	
	Unknown	0	6	
	Total Deleted	31	6	100 B
Query Sent	Completed	5	0	1.0
	Deleted	1	0	1.0
	Total Queries	б	0	
*Queries were not sent to hospit *Reports deleted categories wer				

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 Preva- lence	Male	Female	Preva- lence Ratio (M\F)	Non- His panic White	Non- His panic Black	His- panic	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 <u>Staff</u>

#### **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

• Tr	ansaction log is i	mportant	9 0 4 4 5 4 4 1 5 5 1 5 1 mm, 3 COB to be been (freq) Transition for
	- Identify report		And the set of the set
	- Code reasons f	•	
• Fil	e uploads for lar	ger hospitals	The second
	- Flag errors by typ any errors	pe and record num	ber and reject files with
	- Check for gaps in	n reporting	
	- Check for gaps in		
	- Expect duplicate		

## Converting to a Web-Based System Tips & Recommendations

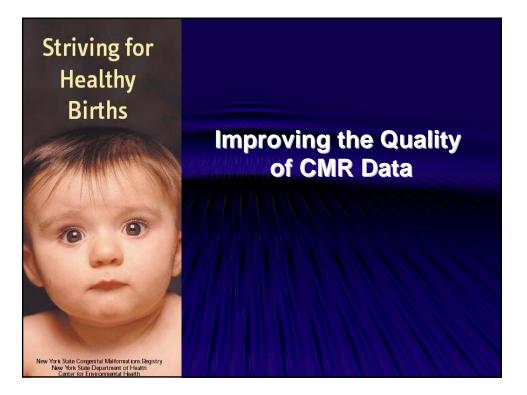
- Routine data QA/QC programs and procedures
- Provide clear instructions and good documentation
  - Electronic handbook
  - Reportable malformations

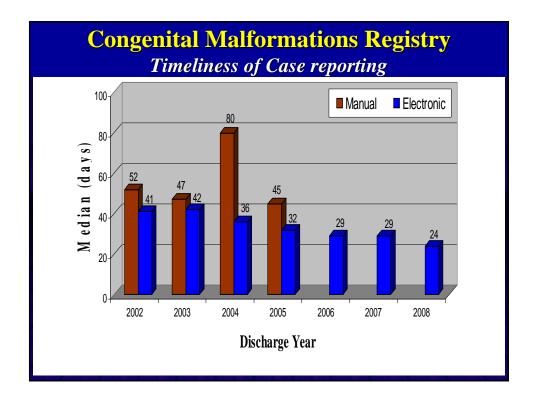
#### Hospital communication and feedback

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

• Contact other programs for advice/assistance







			Cases v unspecifie	% of cases with unspecified codes by reporting system			
Selected birth defect category	BPA codes (unspecified BPA codes)	Total	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 palvis/ureter	753.2 (753.290)	4,299	353	8.2	12.7	3.5	<0.001
Total selected cases		7,706	750	9.7			

# 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

lategory	New York	Upstate			
	City	NY	New York State	NBDPN 1999-2001	95% CI Range
ous system defects us without anencephalos ele	0.3 1.6 0.4	0.5 2.2 0.6	0.4 1.9 0.5	2.5 3.7 0.9	2.3-2.7 3.4-3.9 0.8-1.0
na/ microphthalmia	0.6	0.9	0.8	2.1	1.9-2.3
uncus n of great arteries f Fallot cushion defect	1.0 3.6 4.8 2.6 2.1	0.4 4.7 4.9 3.1 2.8	0.7 4.2 4.9 2.8 2.5	0.8 4.7 3.9 4.4 2.4	0.7-0.9 4.5-5.0 3.8-4.2 4.1-4.6 2.2-2.6
without cleft lip	4.2 5.4	6.5 8.4	5.4 7.0	6.4 10.5	6.1-6.7 10.1-10.9
atresia/ tracheosophageal fistula	2.7	2.0	2.4	2.4	2.2-2.6
etal defects leformity, upper limbs leformity, lower limbs is le	1.4 0.7 1.4 1.1	2.1 1.0 2.5 1.4	1.8 0.9 2.0 1.3	3.8 1.9 3.7 2.1	3.5-4.0 1.7-2.1 3.5-4.0 1.9-2.3 2.7-3.1
al defects rome(trisomy 21)	0.9 11.0 0.9	0.9 13.6 1.1	0.9 12.4 1.0	1.3 13.7 2.4	1.2-1.5 13.2-14.1 2.2-2.6
	a without anencephalos ele ana/ microphthalmia Lad defects uncus for a set of the set is a set of the set of the set is a set of the set of the set is a set of the set of the set of the set is a set of the set of the set of the set of the set is a set of the set of t	ele 0.4 min/ microphthalmia 0.6 Lat defects uncur 1.0 on of great atteries 3.6 f Falot 48 cuthion defect 2.6 left heart syndrome 2.1 fects without cleft ipp 4.2 th and without cleft palate 5.4 inal defects atterial trachesophageal fittula 2.7 large interlinal atteria/stenosis deformity, upper limbe 1.4 deformity, upper limbe 1.4 leformity, lower limbe 0.7 is 1.4 le 1.1 atte hermia 1.8 al defects in 0.9 forme(trisomy 21) 11.0	ele         0.4         0.6           nia/ microphthalmia         0.6         0.9           lar defects         1.0         0.4           uncue         1.0         0.4           or of great atteires         3.6         4.7           f Fallot         4.8         4.7           leath heat syndrome         2.6         3.1           left heat syndrome         2.6         3.4           fets         4.2         6.5           maid defects         3.4         4.7           atterial trachesophageal fittula         2.7         2.0           large intestinal attesia/stenoisis         4.4         4.7           deformity, upper limbs         1.4         2.1           atchormity, upper limbs         1.4         2.5           is         1.1         1.4         2.5           al defects         1.8         2.5         3.5           al defects         1.8         2.5         3.6           is the mria         1.8         2.5         3.6	ele       0.4       0.6       0.5         nia/ microphthalmia       0.6       0.9       0.8         lar defects       0.0       0.7         uncur       1.0       0.4       0.7         or of great arteries       3.6       4.7       4.9         d Fallot       2.6       3.1       2.8         lear heart synchrone       1.0       1.4       2.8         left heart synchrone       2.8       5.4         fets       without cleft lip       4.2       6.5         inal defects       3.4       4.7       2.4         large intersinal arteria/stenoris       4.4       4.7       4.6         eid defects       1.4       2.1       1.8         atcominy, upper limbs       1.4       2.5       2.0         is is charmia       1.8       2.5       2.0         is ic hernia       1.	ele     0.4     0.6     0.5     0.9       nia/ microphthalmia     0.6     0.9     0.8     2.1       lar defects     1.0     0.4     0.7     0.8       or of great arteries     3.6     4.7     4.2     4.7       f Fallot     2.6     3.1     2.8     2.4       lex hein defect     2.6     3.1     2.8     2.4       fects     without cleft lip     4.2     6.5     5.4       inal defects     3.4     2.4     10.5       inal defects     2.7     2.0     2.4       aterait trachesophageal fittula     2.7     2.0     2.4       ised defects     3.4     2.5     2.4       deformity, upper limbs     1.4     2.1     1.8       atcharing, upper limbs     1.4     2.1     1.8       is chorning     1.8     2.5     2.0     3.7       is the traina     1.8     2.5     2.9     3.2       adde



## **Contact Information**

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