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**



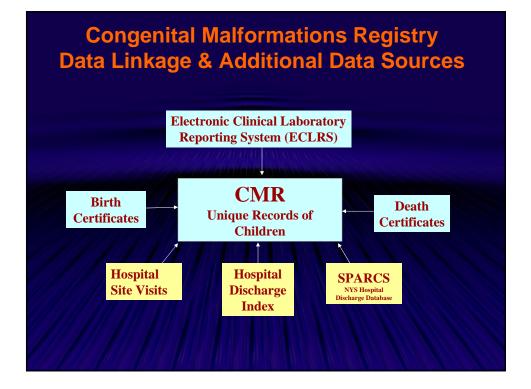
Electronic Card File 1980's "Technology" Statewide - approximately 250,000 to 300,000 births annually

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

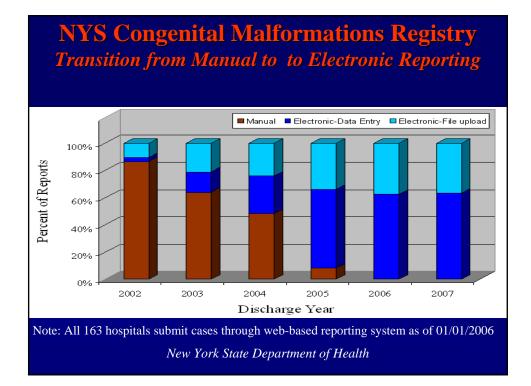
Cases can be diagnosed with 20+ major malformations

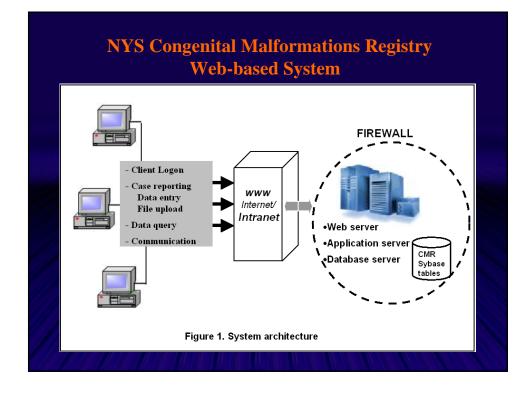
Cases can be reported multiple times from one or more hospitals & by physicians up to the age of 2

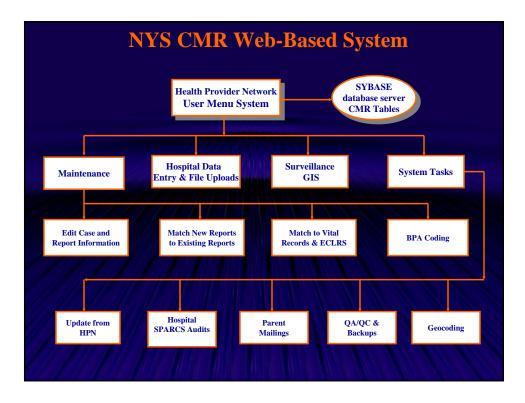
Reports from all sources are maintained and linked with a unique case number

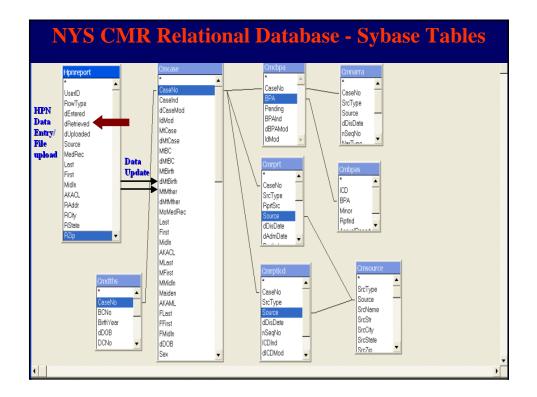


| <b>Routine Hospital Reports</b>                    | 16,508 | 82.6% |
|--|--------|-------|
| Hospital Discharge Index                           | 1,810  | 9.1%  |
| Hospital Discharge<br>(SPARCS) Audit               | 1,524  | 7.6%  |
| Hospital Site Visit                                | 108    |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











|                                      |   | (  | CMF                                      | R Ma   | anda   | tory                      | Ac        | cess        | Co               | ntro   |   |   |                                     |              |
|--------------------------------------|---|--|--|--|--|---------------------------|-----------|-------------|------------------|--|---|---|-------------------------------------|--------------|
| File Edit View                       | v Favorites   | Tools He   | -  |  |  |                           |           |             | 2                | _  |   | _   |                                     |              |
| G .<br>Back                          | Forward   | Stop   | 2<br>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 " |
| User ID:<br>Application              |   |  | Name:                                    | istry  | Select a<br>and/or Ap<br>Help<br>Lookup U  | plication                 |           |             | A                | CM   |   |   | Grant<br>nissio                     |              |
| Application<br>User ID<br>Permission | pkc02   | ake02 ceh  | emr hospite                              | d all all  | Delete<br>Help<br>Change A<br>View Adm<br>Permissio  | ninistrati                | ve Access |             | ine)             |  |   |   |                                     |              |
| Select Para                          | meters for  | Adding u   | sers to ceh                              | <b>cmr -</b> mul   | tiple selec  | tions are                 | allowed u | sing shift/ | control l        | ceys in the  | ese sel                                 | ection v                                    | vindows                             |              |
| Select<br>hospital                   | 0306 Ad<br>0324 Ad<br>0001 Al<br>0002 Al<br>0004 Al | lirondack I<br>lirondack I<br>bany Medi<br>bany Medi<br>bany Mem | Medical Cer<br>cal Center                | nter - Lake<br>nter - Sara<br>Hospital<br>South Clini<br>tal | Placid Site<br>nac Lake S<br>ical Campus<br>ter, LLC   | ite                       |           |             | Lis<br>Lis<br>Ap | t All Curi<br>t All Curi<br>plication<br>plication | r Acces<br>rent Us<br>rent Us<br>Permis | sses by<br>ers by N<br>ers for 1<br>sion Ba | <u>Jame</u><br>Bulkmail<br>stch Dow | mload        |
| User ID>                             | pkc02   |  | Delete Perm<br>nsert Perm<br>Select Perm | nission For<br>ission For<br>nission For                     | his Applicat<br>r This Applic<br>This Applic<br>This Applic<br>r This Applic<br>r This Appli | cation<br>ation<br>cation |           |             | Ad<br>He<br>Ser  | _  | : Comn                                  | nents                                       |                                     |              |
|                                      |   |  |  |  |  |                           |           |             |                  |  |   |   |                                     |              |

| 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  |  |  |  |  |  |

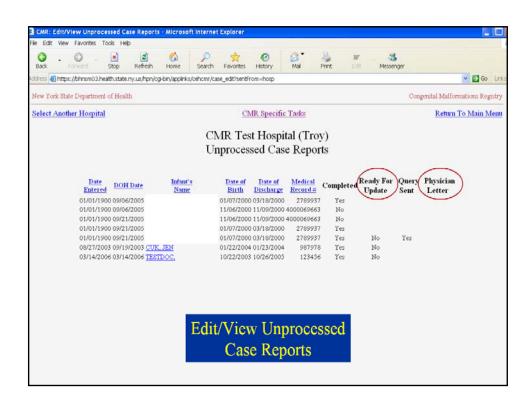
| New York State Department of Health       Screen 1       Congenital Malformations Registry         Help Entering Date       Return to Main Menu         Routine Current Case Report         Child's Information:         PFI Number:         DOH Date:         Medical Record Number:         Child's Last 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   |
|--|---|-----------------------------------|--|
| Child's Information:  PFI Number: DOH Date:  PFI Number: Child's Laformation number: It is the first four digits of SPARCS hospital ID number. Piease fill this in since it identifies by another name, enter the name: State: Date of Birth control of State is in the control of t   | New York State Department of Health                               | Hospital Data Entry<br>Screen 1   | Congenital Malformations Registry                          |
| 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:  |                                   |  |
| Medical Record Number:         Child's Last Name:         Child's Last Name:         First Name:         Middle Initial:         It child has been indentified by another name, enter the name:         Street Address:         City:         State:         Zip Code:         Date of Birth (middlypyy):         Birth Status:         State:         Wire and this facility:         State:         Wire and this facility:         Date of Discharge  |   | 3 1 - Microsoft Internet Explorer | FOX  |
| 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        |  |
| Child's Last Name:       Please fill this in since it identifies your hospital for CMR data entry. There is a list of hospital names with corresponding PFIs in the back of the handbook.         Middle Initial:       Please fill this in since it identifies your hospital for CMR data entry. There is a list of hospital names with corresponding PFIs in the back of the handbook.         Middle Initial:       Please fill this in since it identifies your hospital for CMR data entry. There is a list of hospital names with corresponding PFIs in the back of the handbook.         State:       Please fill this in since it identifies your hospital for CMR data entry. There is a list of hospital names with corresponding PFIs in the back of the handbook.         State:       Please fill this in since it identifies your hospital for CMR data entry. There is a list of hospital names with corresponding PFIs in the back of the handbook.         Date of Discharge (nam/ddyyyy):       Child's Information         State:       In this facility:         If not to ariting facility.       First 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.         Born at this facility:       In the sing facility.         If not to aritis facility:       In the child's mother:         Date of Discharge (nam/ddyyyy):       S.         Date of Discharge (nam/ddyyyy):       S.         Date of Discharge (nam/ddyyyyy):       S.         Date of Datath (ma/d   |   | identification number. It is t    | he first four digits of SPARCS hospital ID number.         |
| <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 |
| All date minal:       Image: Street Address:         Street Address:       Image: Street Address:         City:       State:         State:       Image: Street Address:         Child's Information       Street Address:         Date of Birth (min/datypyy):       Image: Street Address:         Birth Status:       Image: Street Address:         Race:       Image: Street Address:         It is panic:       Image: Street Address:         Race:       Image: Street Address:         It is panic:       Image: Street Address:         It is panis facility:       Image: Street Addr   | First Name:   |                                   |  |
| If child has been indentified by another name, enter the name:<br>Street Address:<br>Child's Information<br>3. Child's Name:<br>3. Child's Name:<br>4. Ast name: A Required Field The child's last name as listed on the birth<br>certificate. The last name may be hyphenated. Do not use special characters<br>such as apostrophes or periods.<br>5. First name: On tuse "malefemale child", B/G / B/B, or mother's first<br>name. Please leave blank if child is not named.<br>6. M.L: The child's inder initide.<br>4. AKA: Use this field for name(s) different from the child's last name listed<br>above. If the child has been identified by another name. The name may be hyphenated. Do<br>not use special characters such as apostrophes or periods.<br>5. Address: The child's current street address, city, state, and zip code. Correct<br>speling of the street, townicity and an accurate zip code are important for<br>computerized geocoding.  | Middle Initial:   |                                   |  |
| City:  | If child has been indentified by another name, enter th           |                                   |  |
| State:       Child's Information         Zip Code:       .         Date of Birth (um/d4/yyyy):       .         Birth Status:       .         Birth wide:       .         State:       .         Birth wide:       .         Born wide:       .     <   | Street Address:   |                                   |  |
| Zip Code:  | City:   |                                   |  |
| Date of Birth (um/d49yyy):       3. Child's Name:         Birth Status: <ul> <li>a. 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>b. First name: Do not use "malefemale child", B/G / B/B, or mother's first name. Please leave blank if child is not named.</li> <li>c. M.I.: The child's middle initial.</li> </ul> Plurality: <ul> <li>a. Last name may be hyphenated. Do not use special characters such as apostrophes or periods.</li> <li>b. First name: Do not use "malefemale child", B/G / B/B, or mother's first name. Please leave blank if child is not named.</li> <li>c. M.I.: The child's middle initial.</li> </ul> Plurality: <ul> <li>mothers at this facility:</li> <li>mother at this facility; hospital of birth:</li> </ul> Date of Discharge (num/d49yyy):             Deceased: <ul> <li>Child's middle initial and course type coding.</li> <li> <ul> <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></li></ul>  | State:  | Child's Information               |  |
| Birth Status:       •         Birth Vergight (growd):       •         Birth Wreight (growd):       •         Sex:       •         Race:       •         Hispanic:       •         Plurality:       •         Born at this facility:       •         Born at this facility:       •         Date of Discharge (new/ddyyyy):       •         Dete of Death (mm/ddyyyyy):       •         Date of Death (mm/ddyyyyy):       •   | Zip Code:   |                                   |  |
| Birthweight (gemo):       a. Last name: A <i>Bequired 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.         Birthweight (gemo):       •         Sex:       •         Withspanic:       •         Plurality:       •         If not a single birth, specify birth order:       •         Born at this facility:       •         Date of Discharge (mm/ddypyy):       •         Date of Death (mm/ddypyy):       •         Date of Death (mm/ddypyy):       •   | Date of Birth (mm/dd/yyyy):                                       | 3. Child's Name:                  |  |
| Birthweight (grumo):       certificate. The last name may be hyphenated. Do not use special characters such as apostrophes or periods.         Sex:       v         Sex:       v         Race:       v         Hispanic:       v         Plurality:       v         Born at this facility:       v         If not a single birth, specify birth order:       v         Hord born at this facility:       v         If not born at this facility:       v         Date of Discharge (num/ddyyyy):       5.         Deceased:       v         Date of Death (num/ddyyyy):       5.         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.  | Birth Status:   | a Last name: A Reg                | ured Field The shild's last name as listed on the birth    |
| Sex:       •         Such as apostophes or periods.         Race:       •         Hispanic:       •         Plurality:       •         Plurality:       •         If not a single birth, specify birth order:       •         Born at this facility:       •         If not a single birth, specify birth order:       •         Born at this facility:       •         If not ons at this facility:       •         Date of Discharge (mu/ddyyyy):       •         Deceased:       •         Date of Death (mu/ddyyyy):       •         Second (mu/ddyyyy):       •         •       •         •       •         •       •         •       •         •       •         •       •         •       •         •       •         •       •         •       •         •       •         •       •         •       •         •       •         •       •         •       •         •       •         •       • <tr< td=""><td>Birthweight (grami):</td><td></td><td></td></tr<>  | Birthweight (grami):  |                                   |  |
| 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.  |
| Hispanic: <ul> <li>C. M.I.: The child's middle initial.</li> </ul> Plurality: <ul> <li>C. M.I.: The child's middle initial.</li> </ul> If not a single birth, specify birth order: <ul> <li>C. M.I.: The child's middle initial.</li> </ul> Born at this facility:                 If not a single birth, specify birth order:               If not born at this facility:               If not born at this facility.               If not born at this facility.               If not born at this facility.               Date of Discharge (nm/ddyyyy):                   Deceased: <ul> <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>   | Race:   |                                   |  |
| If not a single birth, specify birth order: <ul> <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> </ul> <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> <li> <ul> <li></li></ul></li>   | Hispanic:   |                                   |  |
| Born at this facility:       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.         Date of Discharge (nm/ddyyyy):  | Plurality:  |                                   |  |
| Born at this facility:       mother's maiden name, enter the name. The name may be hyphenated. Do not use special characters such as apostrophes or periods.         Date of Discharge (mm/ddypyy):  | If not a single birth, specify birth order:                       |                                   |  |
| If not born at this facility, hospital of birth:       not use special characters such as apostrophes or periods.         Date of Discharge (nu/ddyyyy):       .         Deceased:       .         Date of Death (nu/ddyyyy):       .         Date of Death (nu/ddyyyy):       .   | Born at this facility:  |                                   |  |
| Deceased:<br>Deceased:<br>Date of Death (mm/dd/gygy):<br>Date of Death (mm/dd/gygy):<br>Solution (mm | If not born at this facility, hospital of birth:                  |                                   |  |
| Deceased: spelling of the street, town/city and an accurate zip code are important for<br>computerized geocoding.  | Date of Discharge (mm/dd/yyyy):                                   | 5 Addresses The shild's           | current streat address situ state and tip code Correct     |
| 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<br>Code R | arrative<br>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.<br>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):<br>Social Security Number: | 228.00          | Yes                 | N<br>N         | Hemangiona - skin> 4* diameter<br>(m) Hemangiona, of unspecified site<br>(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)<br>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<br>Von Recklinghsusen's disease   |         |
| Primary Physician's Information:                       | 237.72          | No                  |                | Acoustic neucofibromatosis<br>Neucofibromatosis type II  |         |
| Physician's Last Name:<br>First Name:<br>Address:      | 238.8           | Yes                 | Y<br>Y<br>Y    | Terstons, shoknen<br>Terstons, bask and face<br>Terstons, scale specified sites (please specify site)<br>Terstons, scale: cocycraged       |         |

|                  | Rec                   |                      | Electronic<br>it & Desci |        | ing<br>f Variables   |
|------------------|-----------------------|----------------------|--------------------------|--------|--|
| CMR File Uploads |                       | RRIAGE RET           | URN LINE H               |        | BLE LENGTH RECORDS<br>ER EACH RECORD (Hex: ØDØA)   |
|                  | Variable              | Starting<br>Position | Ending<br>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<br>Should follow US Post Office<br>specifications for abbreviations   |
|                  | City                  | 109                  | 123                      | 15     | Left-aligned   |
|                  | State                 | 124                  | 125                      | 2      | Should follow US Post Office<br>specifications for abbreviations   |
|                  | Zip Code              | 126                  | 134                      | 9      | Left-aligned<br>Hyphen removed in 9 digit Zip<br>Codes (e.g., 12180-2216 as<br>121802216)  |
|                  | Date Of Birth         | 135                  | 142                      | 8      | Required<br>Use form yyymmdd   |
|                  | Birth Status          | 143                  | 143                      | 1      | 0=Missing<br>1=Live<br>2=Still   |
|                  | Birthweight           | 144                  | 147                      | 4      | Right-aligned<br>In grams  |
|                  | Sex                   | 148                  | 148                      | 1      | Required<br>1=Male<br>2=Female<br>3=Undesignated   |
| Upload Failed    | Race                  | 149                  | 149                      | 1      | 0=Missing<br>1=White<br>2=Black or African American<br>3=American Indian/Alaskan Eskimo<br>4=Asian/Pacific Islander<br>9=Unknown |
| Error Report     | Hispanic              | 150                  | 150                      | 1      | 0=Missing<br>1=Yes<br>2=No   |
|                  | Plurality             | 151                  | 151                      | 1      | 0=Unknown<br>1=Single<br>2=Twin<br>3=Triplet<br>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<br>action    | Type of<br>Transaction   | User<br>ID | Infant's Name      | <u>Date of</u><br><u>Birth</u> | <u>Date of</u><br>Discharge | Medical<br>Record # | <u>Date</u><br>Entered<br>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<br>9AM      | Added                    | jlc16      | TEST - TEST,       | 11/02/2003                     | 11/12/2003                  |                     | 11/20/2003                            |
|                   | 0 2003<br>0AM      | Updated                  | jlc16      | TEST - TEST,       | 11/02/2003                     | 11/12/2003                  |                     | 01/01/1900                            |
|                   | 2003<br>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<br>Number | Name (City)                                       | New<br>Reports | Number Ready<br>To Update | Incomplete<br>Reports |       | f Date Of<br>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:<br>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<br>Name:   | 1st Letter Sent:<br>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<br>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<br>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.<br>4. This chromosome related anomaly was reported.<br>Please list the results of the chromosome studies/n<br>chromosome studies were performed.<br>All diagnosis of anomalies listed as a ICD9 code of   | ame of cytogenic lab where<br>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<br>of 758 and 255.2 and 752.7<br>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<br>of 758 and 255.2 and 752.7<br>agnosis. If this child was not<br>information is not available                            | ible, please |
| <ul> <li>indicate if verified or ruled out.</li> <li>4. This chromosome related anomaly was reported. [<br/>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<br>of 758 and 255.2 and 752.7<br>agnosis. If this child was not<br>information is not available<br>e child's pediatrician. | ible: please |
| indicate if verified or ruled out.<br>4. This chromosome related anomaly was reported.<br>Please list the results of the chromosome studies/n<br>chromosome studies were performed.<br>All diagnosis of anomalies listed as a ICD9 code of<br>require chromosome study results to confirm the di-<br>born in your facility and therefore the chromosome  | ame of cytogenic lab where<br>of 758 and 255.2 and 752.7<br>agnosis. If this child was not<br>information is not available<br>e child's pediatrician. | ible: please |

| Edit View Favorites    | Tools Help   |   |
|------------------------|--|---|
| Back 🔹 🕥 🕤 💌           | 😰 🏠 🔎 Search 🤸 Favorites 🤣 🍰 🖩                                       | 1 - 🖵 🍇   |
| 🕫 🔕 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<br>; 'NOS or NEC" must be more specific. |
|                        | Response:  |   |
|                        | aortic valve stenosis  | ×   |
| Send Response          | <u>Return To Main M</u>  | Hospital Query  |

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|---|---|
| CMR Specific Tasks                                  |   |
| 1   | Menu<br>Options<br>Available to<br>CMR<br>Staff |
| <u>Birth Defects Surveillance in New York State</u> |   |

|                |          |                      |     |       | Ca               | se          |             |         | <b>charge Inform</b><br>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<br>Туре | Source   | Date of<br>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<br>756710 |             | Y<br>Y      | N       | Megalogastria<br>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<br>3068: Albert Einstein Gollege of<br>0325: Alice Hydre Memorial Hoss<br>0482: Amsterdam Memorial Hoss<br>0116: Arnot Ogden Medical Cent<br>0085: Auburn Memorial Hospital<br>0739: Aurelia Osborn Fox Memo<br>0746: Bassett Health Care<br>1438: Bellevue Hospital Center<br>0848: Bellevue Woman's Hospit | Medicine —<br>pital<br>pital<br>ter<br>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<br>2007 - 12 / 2007<br>January 15, 2008 |  | $\frown$ |
|---|-----------------------------------|---|--|----------|
| Average number of days bet  | ween discharge date and date of 1 |   |  | 22 days  |
|   | Category                          | Monitoring Period<br>(2007)<br>Number of Reports              | Baseline Average<br>(2000-2004)<br>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<br>*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<br>location | Total<br>children | Total<br>Preva-<br>lence | Male  | Female | Preva-<br>lence<br>Ratio<br>(M\F) | Non-<br>His<br>panic<br>White | Non-<br>His<br>panic<br>Black | His-<br>panic | Other &<br>Unknown<br>Race | Mothers<br>Age<br><35yrs | Mothers<br>Age<br>>=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<br>COB to be been (freq)<br>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<br>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

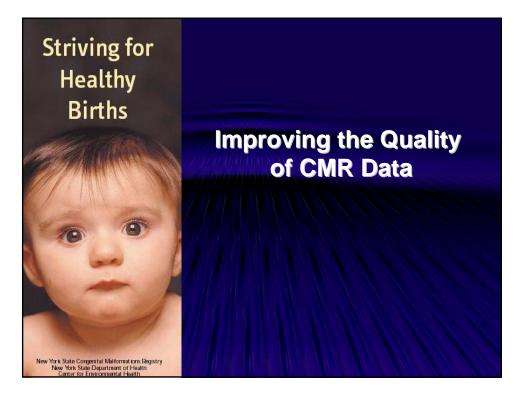
- Routine data QA/QC programs and procedures
- Provide clear instructions and good documentation
  - Electronic handbook
  - Reportable malformations

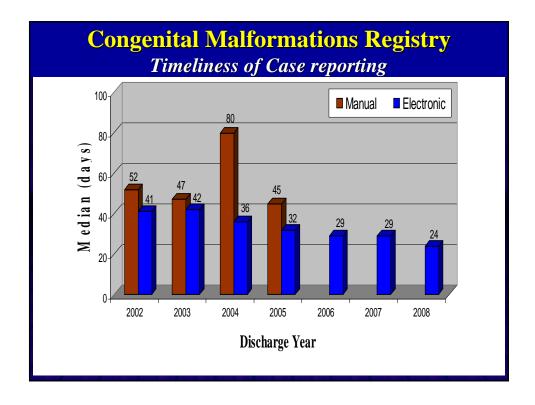
#### Hospital communication and feedback

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

• Contact other programs for advice/assistance







|  |  |       | Cases v<br>unspecifie | % of cases with unspecified<br>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<br>State  | NBDPN<br>1999-2001   | 95% CI<br>Range  |
| ous system defects<br>us<br>without anencephalos<br>ele                      | 0.3<br>1.6<br>0.4  | 0.5<br>2.2<br>0.6  | 0.4<br>1.9<br>0.5  | 2.5<br>3.7<br>0.9  | 2.3-2.7<br>3.4-3.9<br>0.8-1.0  |
| na/ microphthalmia   | 0.6  | 0.9  | 0.8  | 2.1  | 1.9-2.3  |
| uncus<br>n of great arteries<br>f Fallot<br>cushion defect                   | 1.0<br>3.6<br>4.8<br>2.6<br>2.1  | 0.4<br>4.7<br>4.9<br>3.1<br>2.8  | 0.7<br>4.2<br>4.9<br>2.8<br>2.5  | 0.8<br>4.7<br>3.9<br>4.4<br>2.4  | 0.7-0.9<br>4.5-5.0<br>3.8-4.2<br>4.1-4.6<br>2.2-2.6  |
| without cleft lip  | 4.2<br>5.4   | 6.5<br>8.4   | 5.4<br>7.0   | 6.4<br>10.5  | 6.1-6.7<br>10.1-10.9   |
| atresia/ tracheosophageal fistula  | 2.7  | 2.0  | 2.4  | 2.4  | 2.2-2.6  |
| etal defects<br>leformity, upper limbs<br>leformity, lower limbs<br>is<br>le | 1.4<br>0.7<br>1.4<br>1.1   | 2.1<br>1.0<br>2.5<br>1.4   | 1.8<br>0.9<br>2.0<br>1.3   | 3.8<br>1.9<br>3.7<br>2.1   | 3.5-4.0<br>1.7-2.1<br>3.5-4.0<br>1.9-2.3<br>2.7-3.1  |
| al defects<br>rome(trisomy 21)   | 0.9<br>11.0<br>0.9   | 0.9<br>13.6<br>1.1   | 0.9<br>12.4<br>1.0   | 1.3<br>13.7<br>2.4   | 1.2-1.5<br>13.2-14.1<br>2.2-2.6  |
|  | a without anencephalos<br>ele<br>ana/ microphthalmia<br>Lad defects<br>uncus<br>for a set of the set<br>is a set of the set of the set<br>is a set of the set of the set<br>is a set of the set of the set of the set<br>is a set of the set of the set of the set of the set<br>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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