New York State Department of Health

Birth Defects Registry (BDR) Handbook

Reporting Guidance
for Hospitals and Healthcare Facilities

August 2023

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Revision History

Section(s)	Date	Description
All	November 2021	Initial version released
How to Look up your HCS Coordinator	January 2022	Updated with new "ComDir Search and Export tool" steps
Summaries	January 2022	Provided alternate method to receive Report Card and Reports by Year
Enter Reports Appendix 1	January 2022	Clarified non-liveborn reporting and file upload guidance
Contacts	August 2023	Updated Director contact
Appendix 1	August 2023	Updated guidance

Foreword

The Birth Defects Registry (BDR) (formerly Congenital Malformations Registry (CMR)) of the New York State Department of Health (NYSDOH) has prepared this handbook to provide hospitals and other healthcare facilities with guidance for submitting reports to the Registry. This handbook contains information on reporting to ensure completeness and accuracy in the preparation of reports. It also contains information on policies within the Department.

To assist those responsible for submitting reports to the BDR and to improve the quality of Registry data, new materials and updated information will be emailed as needed to application users and anyone who is listed as a hospital contact or has requested to receive updates. This handbook is provided for your convenience in keeping Registry information together as a handy reference.

Please email any comments or suggestions to us at bdr@health.ny.gov.

Birth Defects Registry Contacts

The NYS Birth Defects Registry (also known as the Congenital Malformations Registry) is part of the Bureau of Environmental and Occupational Epidemiology (BEOE), which is in the NYSDOH Center for Environmental Health.

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Registry Contacts:

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> Empire State Plaza -Corning Tower, Room 1203
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>
> Phone: (518) 402-7950
> E-mail: BDR@health.ny.gov

Website:
> Further information can also be found on the NYS Department of Health's website at http://www.health.ny.gov/birthdefects.

General Information

About Birth Defects

Every 4.5 minutes, a baby is born with a birth defect. Major birth defects are conditions present at birth. They include structural changes in one or more parts of the body and biochemical abnormalities that lead to illness. They can have a serious, adverse effect on health, development, or functional ability. The possible association between environmental contaminants and human health problems is an important concern.

- In the U.S., 3% (one in 33) live births have a major structural or genetic birth defect.
- In New York State, close to 12,000 infants are reported to the BDR every year with birth defects. www.cdc.gov
- Hospitalization costs due to birth defects are disproportionally high, accounting for 3% of all hospitalizations and 5.2% of total hospital costs. In 2013, hospital costs in the U.S. for birth defects totaled $22.9 billion.
- Birth defects are responsible for 20% of infant deaths in children less than one year of age - causing one in every five deaths.
- Effects of birth defects can range from mild to severe and can result in debilitating illness, long-term disability, or death.
- Defects of the heart are the most common kind of birth defect and cause most of the hospitalizations.
- Causes of most birth defects are unknown.
- New Yorkers are concerned about the possible association between birth defects and environmental contamination.

Why the Registry is Important for Public Health

The NYS BDR is the best statewide source of information about birth defects in children born or residing in NYS, and it is the second largest statewide population-based birth defects registry in the nation. By monitoring routinely collected reports, public health staff are able to identify and investigate unusual patterns of birth defects throughout NYS and study suspected causes of certain conditions. Analysis of BDR information helps public health scientists understand the frequency, variety and pattern of birth defects in NYS. This information is used to:

- Identify changes in birth defect rates over time that may signal a change in women's health, environmental conditions, and other factors.
- Identify geographical areas with consistently high rates.
- Provide summaries and tables to the public, health providers, local health departments, and others, upon request.
- Efficiently investigate reports of unusual numbers of birth defects.
- Ensure that families of children identified in the Registry locate available resources so that each child can maximize his or her development.
- Identify families of children with specific defects who may be invited to participate in research studies.

On the NYSDOH website, the BDR publishes birth cohort reports that summarize birth defects by type, organ system and county. The demographics of children with reported defects are summarized.

Comparisons are also made with birth defects prevalence rates in other states. Additional information about the prevalence of birth defects in New York State are available through the Environmental Public Health Tracker or the birth defects section of Health Data NY. These data and reports serve as resources for healthcare programs and professionals providing preventive healthcare and delivering services to affected children and their families. A number of health research studies using registry data have been published. A bibliography and copies of articles that use BDR data are available and information about causes and prevention of birth defects, as well as resources for families and professionals, is available on the BDR's webpage. These data and reports serve as resources for healthcare programs and professionals providing preventive healthcare and delivering services to affected children and their families.

How the Registry Obtains Information

Hospitals (as defined in Article 28 of Public Health Law), physicians, nurse practitioners qualified to diagnose birth defects, physician assistants qualified to diagnose birth defects, and midwives throughout NYS are required by law to report children born or living in NYS who have been diagnosed before **two years** of age with major birth defects. For certain birth defects, reporting is required for children diagnosed before **ten years** of age as denoted in the ICD-10 Coding Manual. In 2016, birth defects diagnosed in a fetus also became reportable. The registry also allows for reporting of non-liveborn fetuses with a birth defect and all stillbirths regardless of birth defect status. The registry has a web-based reporting application called "Birth Defects Registry". The majority of reports in the Registry are currently submitted by hospitals, from whom we request both inpatient and outpatient information. The BDR application on the NYS Health Commerce System (HCS) also allows physicians and other healthcare providers to report electronically as well.

NYS clinical laboratories also report to the NYSDOH through the Electronic Clinical Laboratory Reporting System application when test results confirm diagnosis of a genetic or chromosomal birth defect.

How Information is Kept Confidential

DOH staff rigorously secure and protect all Registry information in order to maintain and uphold a high level of privacy and confidentiality. Access to Registry information is restricted and carefully monitored so that the identity of children and families is not disclosed. The NYS Department of Health's Institutional Review Board for the Protection of Human Subjects must approve any research projects for which families are contacted. If a child is adopted, neither the birth parents nor the adoptive parents are contacted. When information is provided to communities to help them plan for services, no names are attached to the information.

Why the Registry Collects Stillbirth and other Non-Livebirth Reports

A stillbirth is defined as a spontaneous intrauterine fetal death occurring at 20 or more weeks gestation or 350 or more grams delivery weight with unknown gestational age. Stillbirth is a much-understudied birth outcome and results in considerable emotional and psychological impact for affected families. Other non-livebirths include outcomes of fetal death prior to 20 weeks gestation, such as spontaneous abortion or miscarriage, or terminations at any gestational age. There is very limited population-based surveillance data on these birth outcomes, despite the potential for them to be associated with a birth defect. Therefore, ascertainment of such data could provide a more accurate understanding of the prevalence, trends, and potentially the causes of birth defects.

Public Health Laws and Regulations

The Birth Defects Registry was established as part of the Environmental Disease Surveillance Program in 1981, by enactment of Part 22 of the New York Sanitary Code. Part 22.1 requires that every hospital and physician shall submit a supplemental report of spontaneous fetal death. Part 22.3 requires that every physician and hospital in attendance on an individual diagnosed within two years of birth as having one or more congenital anomalies, shall file a supplementary report with the State Commissioner of Health within 10 days of diagnosis.

Data collected by the BDR are, by law, to be used for surveillance and to facilitate epidemiologic research into the prevention of environmental diseases, as prescribed by **Public Health Law 225(5)(t)** in order to reduce morbidity and mortality. Confidentiality of all data reported to the Registry is strictly maintained by DOH staff and rigorously safeguarded by Section 206(1)(j), which specifically prohibits the release of personal identifiers. Families of children reported to the BDR are never contacted for research without prior consent of the Department of Health's Institutional Review Board. If a child is adopted, the family is not contacted.

Public Health Law: Article 2; Title 1: Section 206

Commissioner's General Powers and Duties

1. The Commissioner shall:

    (j) cause to be made such scientific studies and research the furnishing of such information to the commissioner, or his authorized representatives, shall not subject any person, hospital, sanitarium, rest home, nursing home, or other person or agency furnishing such information to any action for damages or other relief. Such information when received by the commissioner, or his authorized representatives, shall be kept confidential and shall be used solely for the purposes of medical or scientific research or the improvement of the quality of medical care through the conduction of medical audits. Such information shall not be admissible as evidence in any action of any kind in any court or before any other tribunal, board, agency, or person.

The statutory authority for Part 22 is Section 225(5)(t) of the Public Health Law.

5. The Sanitary code may:
    (t) facilitate epidemiological research into the prevention of environmental diseases, when such research is conducted pursuant to paragraph (j) of subdivision one of section two hundred six of this chapter, by establishing regulations designating as environmentally related diseases those pathological conditions of the body or mind resulting from contact with toxins, or teratogens in solid, liquid or gaseous form, or in the form of ionizing radiation or nonionizing electromagnetic radiation, and by requiring the reporting of such diseases or suspected cases in such diseases to the department by physicians, medical facilities and clinical laboratories. Any information provided to the department pursuant to such regulations shall be in the form required by the department and shall be kept confidential and used by the commissioner pursuant to the provisions of paragraph (j) of subdivision one of section two hundred six of this chapter, and other applicable laws relating to the confidential treatment of patient and medical data.

Codes, Rules and Regulations

State Sanitary Code: 10 NYCRR Part 22 – Environmental Diseases

§ 22.1 Supplementary reports of spontaneous abortions and fetal deaths for epidemiologic
surveillance; filing. Every physician and hospital shall file a supplemental report with the State
Commissioner of Health of each spontaneous abortion or other fetal death occurring naturally.
Such report shall be filed within 10 days of the occurrence of such event on such forms as may
be prescribed by the commissioner to facilitate epidemiologic investigation and surveillance.

Revisions below took effect on May 25, 2016:

§ 22.3 Supplementary reports of certain birth defects for epidemiological surveillance; filing.

(a) Every physician, nurse practitioner authorized to diagnose birth defects, physician assistant
authorized to diagnose birth defects, midwife, and hospital as defined in Article 28 of the
Public Health Law, providing health care to a pregnant woman or a child under two years of
age, who diagnoses an embryo, fetus or child as having one or more of the birth defects listed
in Table 1* of this section shall file a supplementary report with the State Commissioner of
Health within 10 days of diagnosis thereof.

(b) Every physician, nurse practitioner authorized to diagnose birth defects, physician assistant
authorized to diagnose birth defects, midwife, and hospital as defined in Article 28 of the
Public Health Law, providing health care to a pregnant woman or a child under ten years of
age, who diagnoses an embryo, fetus or child as having one or more of the birth defects listed
in Table 2* of this section shall file a supplementary report with the State Commissioner of
Health within 10 days of diagnosis thereof.

(c) Every clinical laboratory that conducts diagnostic testing on New York State residents to detect
or confirm the diagnosis of genetic or chromosomal anomalies listed in Tables 1* and 2* shall,
upon detecting or confirming such a genetic anomaly, file a supplementary report with the
State Commissioner of Health within 30 days of detection or confirmation.

(d) Such report shall be on such forms, which may include electronic forms, as may be prescribed
by the commissioner to facilitate epidemiological investigation and surveillance.

*The ICD-10 Reportable Congenital Malformations Coding Manual should be referenced for the most
up to date tables of reportable birth defects.*

Section 2733 of the Public Health Law

1. Birth defects and genetic and allied diseases shall be reported by physicians, hospitals, and
persons in attendance at birth in the manner on and such forms as may be prescribed by the
commissioner.

2. Such reports and information shall be kept confidential and shall not be admissible as
evidence in an action or proceeding in any court or before any other tribunal, board, agency, or
person. The commissioner may, however, publish analyses of such information from time to
time for scientific and public health purposes, in such manner as to assure that the identities of
the individuals concerned cannot be ascertained.

The Health Insurance Portability and Accountability Act of 1996 (HIPAA)

The BDR is authorized by Public Health Law 225(5)(t) to collect data for the purposes of surveillance
and epidemiologic research. Public Health entities are exempt from the HIPAA-related Privacy Rule.

Reporting to the BDR, therefore, is included under section 164.512(b) of the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

Under 45 CFR §164.512(b) of the HIPAA Privacy Rule, covered entities may disclose protected health information without authorization to public health authorities that are authorized by law to collect such information for public health purposes.

§ 164.512 Uses and disclosures for which an authorization or opportunity to agree or object is not required.

(a) *Standard: Uses and disclosures required by law.* (1) A covered entity may use or disclose protected health information to the extent that such use or disclosure is required by law and the use or disclosure complies with and is limited to the relevant requirements of such law.

(i) A public health authority that is authorized by law to collect or receive such information for the purpose of preventing or controlling disease, injury, or disability, including, but not limited to, the reporting of disease, injury, vital events such as birth or death, and the conduct of public health surveillance, public health investigations, and public health interventions; or, at the direction of a public health authority, to an official of a foreign government agency that is acting in collaboration with a public health authority.

Reporting Requirements

Who must report birth defects diagnosed in a fetus, embryo, or child:

Hospitals, physicians, nurse practitioners and physician assistants qualified to diagnose birth defects, and midwives providing health care to a pregnant woman or child are required to submit reports for any birth defects diagnosed in a fetus or embryo of a woman living in New York State or a child under age two years born or living in New York State. For certain birth defects, reporting is required for the child if diagnosed before ten years of age.

For purposes of this registry, a birth defect is defined as any structural, functional or biochemical abnormality determined genetically or induced during gestation and not due to birthing events. This includes newborns and pediatric patients with a birth defect even if they are transferred to or from another hospital. Any child with a birth defect who dies in the hospital (inpatient or emergency room) is included. A stillborn or other non-liveborn fetus diagnosed in either a hospital or outpatient setting is also included.

What to Report:

Each child needs to be reported **only once** unless additional birth defects are identified.

All reportable birth defects are found in the *NYS BDR ICD-10 Coding Manual: List of Reportable Congenital Malformations*. All major birth defects must be reported. Therefore, if a child has one or more major birth defect, please report all of them. Minor birth defects (those preceded by (*m*)) should be reported ONLY if the child has a major defect as well. Therefore, if there is major and a minor birth defect, report both. If there is only a minor *(m) defect* present, do not report the child.

The *ICD-10 Coding Manual* contains a complete list of all conditions reportable to the BDR. The file is accessible through the BDR reporting application on HCS under the "Resources" tab. It is also located on the BDR public web page and may be downloaded by going to https://www.health.ny.gov/diseases/congenital_malformations/docs/icd.pdf. The *ICD-10 Coding Manual* includes the following information:

1) ICD Code – The International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10-CM) (effective October 2015) and/or ICD-9-CM code that corresponds to the child's condition. Required field.

2) Birth Defect Description – provide narrative description(s) of the birth defect(s) with specific details (e.g., left side, right side, etc.). Required field.

- **All major birth defects and stillbirths must be reported**
- **Minor birth defects**, descriptions with an *(m)* (e.g. *(m) ankyloglossia*), are **only required to be reported if the child also has one or more major birth defects(s)** or was stillborn.
- Some birth defects are only reportable if the child is a certain sex or was born above a certain birth weight. Please only report them if they meet the given criteria or the criteria is unknown. Examples:
  - Only report patent ductus arteriosus (PDA) if the child's birth weight is 1,500 grams or greater. PDA is normal and necessary as a fetus develops and should close at birth.
  - Only report K40-, inguinal hernia, for female children
- **Include the most specific birth defect description available from the medical record, for each reportable diagnosis/birth outcome.**

- Indicate the laterality if applicable (e.g., talipes equinovarus, left)
- Avoid reporting vague descriptions starting with "other" or with codes ending in -8 or -9
- Check to make sure you entered the most specific diagnosis available, especially if you see "(must specify)" next to an ICD-10 Description

Specific birth defect descriptions are required because several different defects with different causes can be grouped under the same ICD code. When the Registry receives reports, we recode the information provided in the "birth defect description" into a coding system with more specificity. Thus, a general diagnosis is not sufficient, and the report will be queried for a more specific description. Examples of general diagnoses are ICD-10 codes Q24.9 congenital malformations of heart, unspecified, Q35.9 "cleft palate, NOS, as well as all other ICD-10-CM codes with NEC, NOS and Other in the description of the defect. When these diagnoses are received, the reporter will receive a query from Registry staff requesting more information.

Genetic studies: Report results of genetic testing or the name of the genetic laboratory that performed the test in the appropriate field.

Anomalies of indeterminate sex: Report these birth defects with results of chromosome/ genetic testing or with the name of the genetic laboratory that performed the test.
- Example: Q56.1, Male psuedohermaphroditism; Genetic test results: 46 XY karyotype

Unconfirmed, pending, and "rule-out" diagnoses: Please indicate if there is uncertainty surrounding the diagnosis using one of these terms (e.g., Down syndrome – pending karyotype confirmation).

New diagnoses identified in subsequent inpatient or outpatient admissions/ambulatory surgeries/emergency department visits: Each child needs to be reported only once **unless** additional birth defects are found.

Syndromes and conditions that usually include several defects together: When conditions such as Fetal Alcohol Syndrome (FAS) and tetralogy of Fallot (TOF) are reported, all associated birth defect(s) should also be reported. This would include any abnormal facial features associated with FAS. With TOF, ventricular septal defects, pulmonary stenosis or atresia, dextrorotation of aorta, and hypertrophy of right ventricle should all be reported.

When to Report:

According to public health regulations, a birth defect diagnosed in a child must be reported within 10 days (of diagnosis) by a hospital or physician. To make reporting less burdensome, these defects in a maternal or child's medical record should be reported within 30 days of discharge or visit date, unless the facility submits reports through the monthly file upload process. When a child with a birth defect has not been reported within these time periods, the hospital is out of compliance.

Note: See for Frequently Asked Questions regarding reporting.

Failure to Comply with Reporting Requirement:

Failure to comply with requirements to submit data to the BDR as mandated by Section 2733 of the Public Health Law may result in the State issuing your facility a Statement of Deficiency.

How to Report:

Send reports over the internet using the New York State Department of Health's (NYSDOH) Health Commerce System (HCS) Birth Defects Registry Reporting Application (see Online Reporting section).

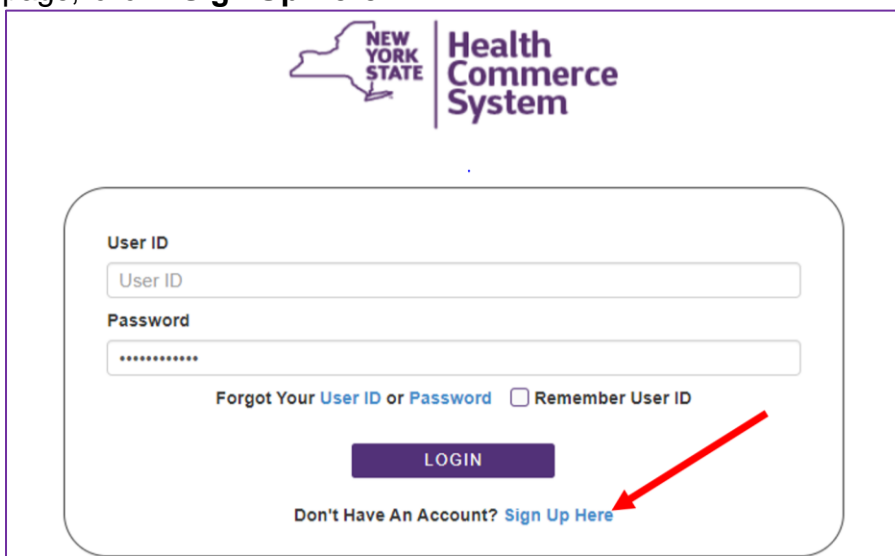# Web-based Reporting through the Health Commerce System (HCS)

The NYSDOH developed the HCS as a secure system for electronically collecting and distributing health related data. The BDR Reporting application on HCS allows you to submit birth defects reports by data entry or file upload, respond to messages from BDR staff, and more. The online BDR Reporting application is the only method for fulfilling the regulatory reporting requirement to submit reports on children or fetuses diagnosed with a birth defect.

Prior to being granted access to the BDR Reporting application, you must have an HCS account.

There are two steps to obtain an HCS account. You must 1) register for an account and 2) enroll your account on the HCS. This second step must be done with your HCS Coordinator. If you don't know who your HCS Coordinator is, call the Commerce Accounts Management Unit (CAMU) at 1-866-529-1890 option 1 (M-F 8am - 4:45pm) or contact the BDR at bdr@health.ny.gov. Anyone with an existing HCS account, such as your supervisor, can also look up your Facility's HCS Coordinator.

Where do I register?

1. Open your web browser and enter this web address in the address bar:
   https://commerce.health.state.ny.us
      a. You could also enter NYS HCS in your internet browser's search bar
2. On the HCS log in page, click **"Sign Up Here"**

3. Respond to the questions
4. Click "**Register** for an account"
      a. Quick Reference Guide
5. Follow the two-step process:
      1) Register for an account
      2) Enroll your account on the HCS. This step must be done with your HCS Coordinator.

      Register only once!

How do I register?

1. Complete the Name, Address and Policy Statement sections, and click **Continue**

NOTE: Your name must match what is on your Photo ID

2. Create a user ID and password, click **Continue**

3. Answer at least six of the 27 secret questions, click **Register**

4. Verify your account information, and click **Confirm**

5. Print your Account Registration Completion information, click **OK**
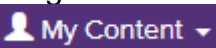
6. Print your confirmation email that your user ID was created

7. See your *HCS Coordinator with your Account Registration Completion email printout and your Photo ID

*If you do not know your HCS Coordinator, please call the **Commerce Accounts Management Unit (CAMU) at 1-866-529-1890 option 1** (M-F 8am-4:45pm) or have someone with HCS access look them up for you following the steps on the next page.

How to Lookup your HCS Coordinator

1. Log in to HCS
2. Under "My content" select "Look up my coordinators"
3. You'll see a list of HCS Coordinators that anyone at your facility can work with to finalize their accounts and/or have roles assigned to them.

Alternatively, you can use the "Comair Search and Export Tool":

1. Log in to HCS

2. Go to the Comdir Search and Export Tool by clicking it under 'My Applications' or navigating to the "All Applications" under "My Content" [My Content ▾] tab at the top right
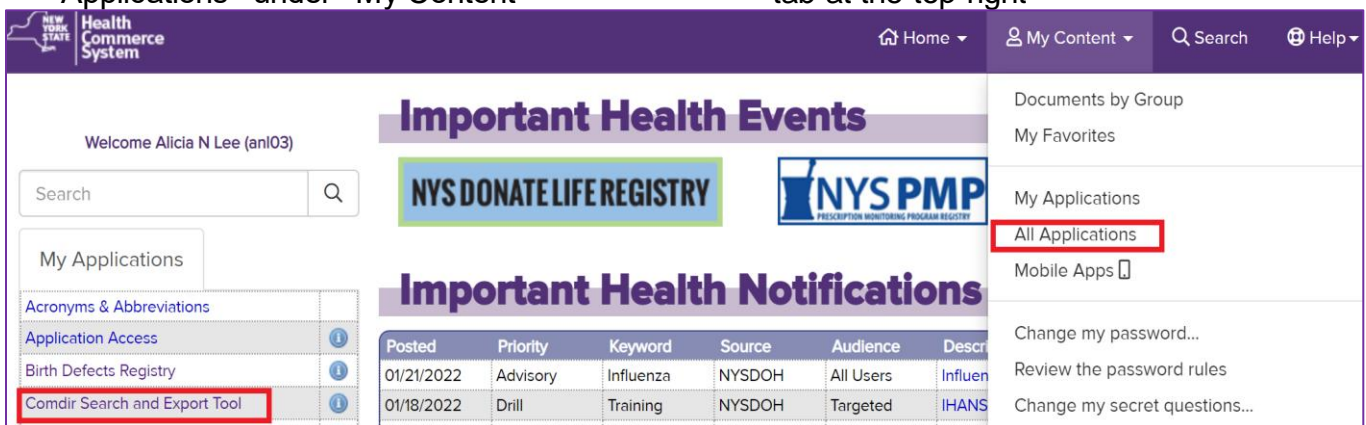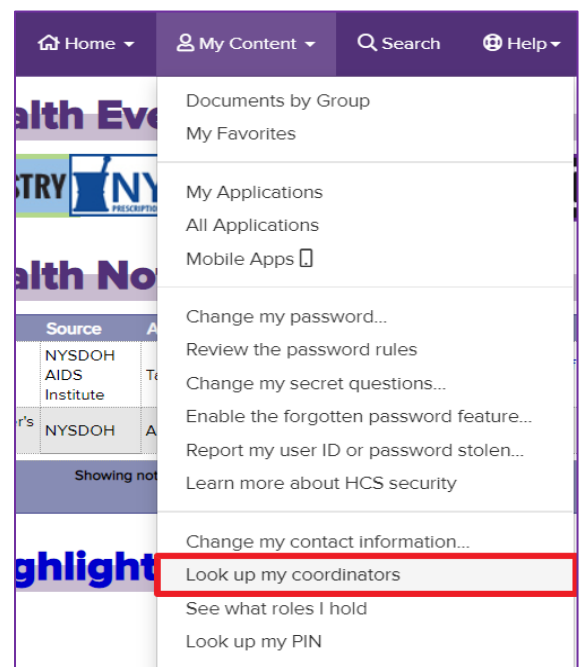
3. Comdir Search and Export Tool- Select Search by Organization (radio button)

4. Use the search fields to type in your "Organization Type", "Organization Name" and select "HPN Coordinator" under "Contact Person Role". Click "Search".

5. The results will appear on the bottom half of the screen:

	Org Type ⇕	Org Name ⇕	Organization ID ⇕	Address ⇕	County ⇕	Region ⇕	Phone ⇕	Fax ⇕
☐	Hospital (pfi) - 4	Z Test Hospital (PFI)	8888	800 North Pearl Street Room 214 Albany NY USA 12204	Albany	Capital District Regional Office	518-473-8144	518-486-3518

6. Select your facility by checking the box to the left of the "Org Type" column. Click on "Search Users" in the right-hand corners:

	Org Type ⇕	Org Name ⇕	Organization ID ⇕	Address ⇕	County ⇕	Region ⇕	Phone ⇕	Fax ⇕
☑	Hospital (pfi) - 4	Z Test Hospital (PFI)	8888	800 North Pearl Street Room 214 Albany NY USA 12204	Albany	Capital District Regional Office	518-473-8144	518-486-3518

7. A list of HPN Coordinators from your facility will appear, along with their contact information. Any of these individuals can assist you in obtaining an HCS account. Export options (CSV, Excel) are also available for these search results.

Role ⇕	Org Type ⇕	Org Name ⇕	Organization ID ⇕	HCS ID ⇕	Primary Organization ⇕	First Name ⇕	Last Name ⇕	Address ⇕	Phone ⇕	Fax ⇕	Email ⌃
HPN Coordinator - 25	Hospital (pfi) - 4	Z Test Hospital (PFI)	8888	tt590457	Z Test Hospital (PFI)	Test parent	Test	800 North Pearl St Albany NY USA 12204	518-473-1809	518-486-1615	aml08@health.state.ny.us

How do I sign on the HCS?

After your HCS Coordinator finalizes your account, you will be enrolled on the HCS and receive an email. Complete the following items:

1. Read the "Security and Use Policy" (SAUP) for rules and responsibilities

2. Click the HCS website link, and enter your user ID and password that you created when registering

Note: Newly enrolled users will receive an email. Existing users will not receive an email.

Request access to BDR application

After getting access to HCS, you have two options:

1) Request access through the HCS:

-Sign into the HCS

-Click on the ![My Content] tab at the top right, then select "All Applications"

-Browse by selecting [B]

-Click the info button ⓘ next to Birth Defects Registry

-Scroll down and click "Request for Access"

-Complete the form, specifying the hospital(s) you are requesting access for (name(s) and PFI(s))

-Click [SEND] and wait for an email response stating you have access

2) Email the following information to bdr@health.ny.gov:

Requestor information:
1. Name:
2. E-Mail Address:
3. Phone Number:
4. HCS Account User ID:
5. Hospital(s) Access is Requested For (Name and PFI):
6. Reason for Access Request:

After you are granted access to the BDR Reporting Application, you will receive an email from BDR notifying you of your access and providing the useful documents for reporting.

Upon receipt of this notification, log out from HCS and log back on. Then you will see **Birth Defects Registry** appear under your list of 'My Applications'.

Once in the BDR application, you can also click **Help** to see a list of resources including this **BDR Handbook** and the **Reportable ICD-10 Codes manual**. **These are the two most important reference documents for reporting to the BDR.**

Tailored training is available for all reporting entities in the state. If your facility has new staff or would like a refresher on reporting, please contact us at bdr@health.ny.gov to schedule a BDR Reporting Demonstration and Best Practices Training session.

Account Information and Tools

Passwords expire every 180 days. You will still be able to access the HCS Portal, but you will be forced to select a new password. An account that has not been used for more than 24 months will need to be reactivated by calling The Commerce Accounts Management Unit (CAMU).

An expired password will be disabled after 24 months. You will not be able to access the portal until your identity has been verified by a CAMU customer service representative at 1-866-529-1890 option 1, from 8:00 a.m. until 4:45 p.m. EST, excluding weekends and holidays.

Note: Clearing your browser cache can help to resolve some issues. We suggest clearing your cache monthly as a standard practice.

The HCS Portal includes a comprehensive suite of tools for managing your account. You can access these tools under "My Content" in the top menu bar on the HCS.

For any account questions, please contact the Commerce Accounts Management Unit (CAMU) at camu@its.ny.gov.

Using the BDR Application on Health Commerce

HCS Login Screen

Each user should log in with their own personal username and password. Sharing of HCS accounts is prohibited and subject to revocation. Multiple instances of violations that compromise the security of account usage may result in the inability of your organization to do business on the HCS.

Locating and Accessing the BDR Application

On the left-hand side of the screen, under "My Applications" click on "Birth Defects Registry."

If "Birth Defects Registry" is not listed under "My Applications", add it by clicking "All Applications" under "My Content" at the top, clicking "B", then scrolling down and clicking on "Birth Defects Registry". You can also click on the info button to the right of "Birth Defects Registry" to request access.

Scroll down:

Click on the green + button to add "Birth Defects Registry" to your "My Applications" list.

Navigating the Birth Defects Registry Application

Once you click on "Birth Defects Registry", if you have access, you will be directed to the BDR Application Home Screen:

If you have access to multiple facilities, you will first see the following main menu:

Use the drop down to select the facility you plan to report under, then click "Submit". **You can only report for one facility at a time.** You will be directed to the Home screen after clicking "Submit".

Always report under the same facility that you use for SPARCS reporting. Hospitals are audited by comparing SPARCS data with hospital reports submitted to the BDR.

The upper right-hand corner will display your affiliated organization and your registered HCS name. To report for a different facility, for which you have access, click the "Change Facility" button on the left-hand menu.

Affiliated with CMR Test Hospital (009999)
Amanda St. Louis

The icon on the top left will hide the menu and widen the screen when clicked. Re-click to see the sidebar menu again.

Submitting Reports to the BDR

There are two secure ways to submit reports to the BDR: Data Entry and File Upload.
- If you want to type in the information from a medical record, click on "Enter"
- If you have a CSV file containing the required information, then click on "Upload"

Enter Reports

- Click "Enter" under "Reports" to submit reports by data entry.

After clicking "Enter", type the medical record number (MRN) for the child (if liveborn) or mother (if non-liveborn) and click "Check Previous Reports":

Please enter the child's MRN, or if a non-livebirth, the mother's MRN to see if there have been previous reports to the BDR.

MRN: * 999888777

Check Previous Reports

If the MRN is new with no potential matches, the data entry screen will open automatically. However, if the MRN or a similar MRN has been previously reported to the BDR by your facility, information from those previous report(s) with potential MRN matches will appear:

MRN Entered: 999888777   PFI Number: 000002

Please select one:

Click 'New Report' or click on the report you wish to add information to.

New Report

Child's MRN ◊	Child's DOB or Date of Delivery ◊	Child's Name ◊	Mother's MRN ◊	Mother's DOB ◊	Mother's Name ◊	Address ◊	City ◊	Discharge Date ▾	Date Submitted ◊
999888777	04/01/2020	Fake, Girly			Fake, Mommy	1 Disney Land	Manhattan	04/04/2020	08/07/2020

Once you confirm the record is the one you want, click on the child's or mother's name to open the data entry screen. Otherwise, click on the "new report" button to open a blank form.

First Four Boxes

At the top of the data entry screen are "Report Type", "Visit Type", "Birth Status" and "Date Reported". Use each drop down to select the appropriate report information for the first three boxes. By default, "Report Type" will be **Routine** and "Birth Status" will be **Live birth**, but these can be changed using the dropdowns. **"**Date Reported" will default to today's date and is not editable.

Report type options (required):

- **Routine** - Most reports will be this type. Choose this option if you are submitting a new report for a child diagnosed with a reportable birth defect at your facility.
- **SPARCS Audit** – Choose this option if you are submitting a report in response to a BDR-SPARCS Comparison Audit conducted by the BDR.

Visit Type options:

- **Inpatient-** select if patient stayed overnight at least one night at your facility
- **Outpatient-** select if patient received non-overnight service at your facility
- **Other-** select for ambulatory surgery or other visit types

Birth Status options (required):

- **Live birth** - Select if reporting a child or infant born alive
- **Stillbirth** - Select if reporting a stillborn infant. A stillbirth is a fetal death occurring at 20 or more weeks of gestation or 350 or more grams delivery weight with unknown gestational age
- **Other non-liveborn-** Select if reporting a fetal death prior to 20 weeks gestation, such as spontaneous abortion or miscarriage, or terminations at any gestational age
    - **Missing gestational age?** If the child was non-liveborn, and you do not have the gestational age to determine if the birth status was Stillbirth or other non-liveborn, please select other non-liveborn.

Date Reported- this box is automatically filled in; no action is required

After updating/selecting the first three boxes, you can begin data entry to complete the report. If "livebirth" is selected, the form will request the child's information first; if you select "stillbirth" or "other non-live born", a form will open with mother's information first. **Please fill in as many fields as possible**. Note that all fields with a red star * must be completed in order to submit the form. Many fields have drop-down boxes to aid in Data Entry.

ⓘ The info box next to each field provides a description of what information is requested and addresses common questions.

Enter Report: Live Birth

Child's Information

MRN (Medical Record Number) (underline: required): The number assigned by the hospital or office. This is critical for follow-up. It should not be more than 17 characters. Do not include dashes, spaces, or preceding zeroes.

Last name (required): The child's last name as listed on the birth certificate. The last name may be hyphenated and include special characters such as apostrophes or periods.

Suffix: If child has a suffix, select it from the drop-down menu. Otherwise, leave blank.

First name: Do not use "male/female child", "baby boy/girl", "B/G / B/B", or mother's first name. Please leave blank if child is not named.

Middle Name: The child's middle name or initial. Leave blank if unknown.

AKA/Other Name: Use this field for name(s) different from the child's last name listed above, for example, the mother's maiden name. The name may be hyphenated. Do not use special characters such as apostrophes or periods.

Street Address (required): The child's current street address. If homeless, enter "Homeless".

Street Address 2: Enter the child's floor, apartment, suite, or any information that would not fit in the "Street Address" box. Otherwise, leave blank.

City: Enter the City, Town, or Borough of the child's current residence. If homeless, enter "Homeless".

State: Select the abbreviation for the US State or Canadian Province of the child's current residence; if the child does not reside in the US or Canada, select "Out of Country". If homeless, select "NY".

ZIP code: Enter the US ZIP code of the child's current residence. It must be a 5 or 9-digit number. If homeless, enter 99999. If a foreign country, enter 88888.

Date of Birth (<u>required</u>): Select or type the child's date of birth with month, day, and 4-digit year using format of mmddyyyy or mm/dd/yyyy.

Gestational Age (in weeks): Enter the completed weeks of gestation (e.g., if child is born at 37 weeks and 6 days, the completed weeks of gestation is 37 weeks).

Birth Weight: Report in grams at birth. Acceptable values are from 250 to 7,500 grams. Do not enter child's weight at subsequent visits. If unknown, leave blank. Note: some defects are not reportable if the child is under a certain birth weight.

Sex (<u>required</u>): Select Male, Female or Undesignated. Undesignated is <u>temporary</u> and sex should be determined by chromosome studies. Each child reported with an undesignated sex will be queried if no chromosome studies were reported. Also, a child reported with undesignated sex should be assigned the ICD-10-CM Q56 (Indeterminate sex and pseudohermaphroditism).

Race: Select the child's race: White, Black (includes African American), Native American (includes American Indian or Alaskan Eskimo), Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, Other Asian, Pacific Islander, Other Race, Unknown, or multi-racial. This is to be answered separately from Hispanic. Race should be reported for Hispanic as well as non-Hispanic children.

Hispanic: Select Hispanic, Not Hispanic, or Unknown. Answer separately from race. If a child is both Hispanic and Non-Hispanic, select Hispanic.

Plurality: Select one: Single birth, Twin, Triplet, Quadruple, Quintuple, Sextuple, or Other. Be sure to count all live and deceased births.

Birth Order: This field should be completed for multiple births only. Select the order in which this child was born: 1st, 2nd, 3rd, 4th, 5th, or 6th. Be sure to count all live and deceased births.

Born at this Facility: select Yes or No.

Hospital of Birth: If the child was not born at your hospital, choose the hospital of birth. Otherwise, select "Other Hospital in NYS State", "Other Hospital outside of NYS State" or "Not born in Hospital" if any of these apply. If no option applies, leave blank.

Discharge date (<u>required</u>): Select or type the date the child was discharged from your hospital with month, day, and 4-digit year (mmddyyyy or mm/dd/yyyy). If the child died while a patient, report the date of death here. For outpatient data, enter the visit date.

Deceased: Select Yes or No.

Date of Death: If child has died, select or enter the date of death with month, day, and 4-digit year (mmddyyyy or mm/dd/yyyy).

Foster/Adopted: Select Foster, Adopted or No. If unknown, leave blank.

Diagnostic Information

ICD Codes and Birth Defect Descriptions (<u>required</u>): Provide ICD-10-CM codes and detailed descriptions of all birth defects. If there are more than three birth defects, click the "add" button to create additional rows. For each ICD code, the specific diagnosis should be stated, not just the main term from the ICD code list. ***Non-specific diagnoses will be queried*** (See What is a Query? section for more details). All diagnosed conditions in the BDR *ICD-10 Reportable Congenital Malformations Coding Manual* should be reported. See examples below:

- Since 2008, we have asked for specificity for ventricular septal defect codes: muscular, peri-membranous, subarterial, etc. This is indicated in the echocardiogram report or consultant notes.
- Include specificity for hypospadias: degree and location e.g., glandular, coronal, penile, subcoronal, perineal, etc.
- Craniosynostosis should include the particular suture(s) involved: sagittal, metopic, coronal, lambdoidal and basilar.
- Provide laterality if appropriate.
- If a specific syndrome is listed as the child's condition, include it in the list, along with all the associated anomalies.

Important: All birth defect descriptions must be specific.

Any diagnosis descriptions that have phrases like "other specified", "unspecified", or "congenital malformation of …" need to be more specific. For example, "congenital malformation of heart" or "other specified congenital malformations of kidney" are too vague. If the birth defect description fails to reveal exactly what is wrong with the child, then the birth defect description is not specific enough

for our purposes. You will need to review the medical record and tell us what the specific birth defect is. Karyotype or chromosome study results are needed for children born in your facility that are diagnosed with chromosomal abnormalities (e.g., Down syndrome, trisomy 21, Edwards syndrome, etc.). If the genetic testing was NOT done through your facility and results are not available, please put a note in the additional information box that says "genetic testing not done through this facility" so that your facility is not queried for this information.

Genetic Studies: If chromosome studies were done, please report the karyotype in long Paris nomenclature. Also report the results of other genetic testing such as genetic sequencing and chromosomal microarray (CMA) tests. If genetic testing was done, but the results cannot be found in the record, please enter the name of the cytogenetic lab or testing facility. If genetic study results will be available in a short time, delay reporting until they are received.

Newborn Screening ID Numbers: The 9-digit code(s) listed on the newborn screening blood collection form(s) or report(s). You will only be able to report this number if your records include the birth admission. If unknown, leave blank.

Additional Information: Write any additional information you would like us to know, or any other comments you may have about this child (e.g., extra address information or additional dx context).

Pulse Oximetry Screening

- **Pulse Oximetry Screening:** Select if screening was done: Yes, No, Refused, or Undetermined.
- **Screening Date:** If screening was done, select or enter the date of screening with month, day, and 4-digit year (mmddyyyy or mm/dd/yyyy).
- **Screening Results:** If screening was done, select the screening result: Pass, Fail, or Unknown.
- **Saturation Values:** If pass/fail not available, provide the saturation values for the hand and foot for initial and repeated screens. The values should be between 0 and 100%.

Pulse Oximetry Screening		
Pulse Oximetry Screening: ⓘ [⌄] if yes, date of Screening: [mm/dd/yyyy] ⓘ		
Screening Results: ⓘ ○ Pass ○ Fail ○ Unknown		
Saturation Values: ⓘ		

	Hand	Foot
Initial Screen:	%	%
Repeat #1:	%	%
Repeat #2:	%	%

Mother's information

Note: If the child is adopted, please provide adoptive parents' information.

Mother's Information

Mother's Last Name:	[ ] ℹ	First Name:	[ ] ℹ	Middle Name:	[ ] ℹ
Maiden Name	[ ] ℹ	Phone Number:	[ ]	Mother's MRN:	[ ] ℹ
DOB (mm/dd/yyyy):	[mm/dd/yyyy] ℹ	SSN:	[ ] ℹ		

- **Mother's Last name**: The last name may be hyphenated and include special characters such as apostrophes or periods.

- **First name:** Mother's first name. Leave blank if unknown.
- **Middle Name:** Mother's middle name or initial. Leave blank if unknown.
- **Maiden Name:** The last name given to the mother at her birth.
- **Phone Number:** Provide the mother's area code and 7-digit phone number (###-###-####). Only enter the mother's phone number in this field.
- **Mother's MRN**: Provide the mother's medical record number. Please obtain this from the mother's medical record if it is not in the child's record. It should not be more than 17 characters. Do not include dashes, spaces, or preceding zeroes
- **DOB (mm/dd/yyyy):** Select or enter the mother's date of birth with month, day and 4-digit year (e.g., 12/31/1999). Please obtain this from the mother's medical record if it is not in the child's record. This information is useful for birth certificate matching.
- **SSN:** The mother's social security number. This number is used to facilitate birth certificate matching. Enter either 9 numbers (no hyphens) or the last four digits of the SSN. This is available with all births and should be reported.

Father's information

Father's Information

| Father's Last Name: | [ ] ℹ | First Name: | [ ] ℹ | Middle Name: | [ ] ℹ |
| DOB (mm/dd/yyyy): | [mm/dd/yyyy] ℹ | SSN: | [ ] ℹ | | |

- **Father's Last Name:** The last name may be hyphenated and include special characters such as apostrophes or periods.
- **First Name**: Father's first name.
- **Middle Name**: Father's middle name or initial. Leave blank if unknown.
- **DOB (mm/dd/yyyy):** Select or enter the father's date of birth with month, day and 4-digit year (e.g., 12/31/1999). Please check admission sheet. This information is useful for birth certificate matching.
- **SSN:** The father's social security number. This number is used to facilitate birth certificate matching. Enter either 9 numbers (no hyphens) or the last four digits of the SSN.

Primary Healthcare Provider's Information

Primary Healthcare Provider's Information					
Provider's Last Name:	[____] ⓘ	First Name:	[____] ⓘ	License Number:	[____]
Provider Type:	[____ ˅]	Address1:	[____] ⓘ	Address2:	[____] ⓘ
City:	[____]	State:	[NY ˅]	ZIP Code:	[____] ⓘ
Phone Number:	[____]				

Include the name and address of the pediatrician or pediatric clinic where the child will receive follow-up care.

- **Provider's Last Name:** The last name of the physician or other healthcare provider who will follow the child. The last name may be hyphenated and include special characters such as apostrophes or periods. If the pediatrician or the name of the clinic where the child will receive care is unknown, leave blank.

- **First Name:** If unknown, leave blank.

- **License Number:** Provider's license number

- **Provider Type:** Please enter the type of provider based on the drop-down list (Licensed Practical Nurse (LPN); Medical Physicist, Medical Health; Midwife; Physician; Physician with 3-year limited license; Physician Assistant; Nurse, RN; Nurse-Practitioner, Acute care; Nurse-Practitioner, Family Health; Nurse-Practitioner, Neonatology; Nurse-Practitioner, Obstetrics and Gynecology; Nurse-Practitioner, Perinatology)

- **Address1, Address2, City, State, ZIP Code (Provider's Address):** The complete address of the provider that will follow the child as an outpatient.

- **Phone Number:** Provider's Phone Number

Submit a report

[Send to BDR] [Clear Form]

Remember to click on "Send to BDR" after completing data entry for each record!

When required information is missing such as child's name, address, date of birth, sex, and date of discharge (or date of outpatient visit for healthcare providers), reports will be rejected and cannot be submitted at all. If you have difficulty with a submission because of missing information, please contact BDR staff at bdr@health.ny.gov.

A summary screen will appear when a report has been sent successfully to the BDR. When you view this information, if there are any errors, you can return to the prior screen and make corrections by clicking "Make Changes to This Report" found at the bottom right. Be sure to hit "Send to BDR" after making changes. Click "Enter Another Report" to work on a different report.

Data Entry: Stillbirth or Other Non-Liveborn

Mother's Information

- **Mother's MRN (required):** The medical record number assigned by the hospital or office. This is critical for follow-up. It should not be more than 17 characters. Do not include dashes, spaces, or preceding zeroes.

- **Mother's Last name (required):** The mother's last name; may be hyphenated and include apostrophes or periods.

- **Maiden Name:** The last name given to the mother at her birth.

- **First name (required):** The Mother's first name; may be hyphenated and include apostrophes or periods.

- **Middle Name:** The mother's middle name or initial; may be hyphenated and include apostrophes or periods. Leave blank if unknown.

- **Phone Number:** Provide the mother's area code and 7-digit phone number (###-###-####). Only enter the mother's phone number in this field.

- **DOB (required):** Mother's date of birth with month, day and 4-digit year; for example, 12/31/1999. Please obtain this from the mother's medical record if it is not in the child's record. This information is useful for birth certificate matching.

- **SSN:** The mother's social security number. This number is used to facilitate birth certificate matching. Enter either 9 numbers (no hyphens) or the last four digits of the SSN. This is available with all births and should be reported.

- **Discharge date(required):** Select or type the date the mother was discharged from your hospital with month, day, and 4-digit year (mmddyyyy or mm/dd/yyyy). For outpatient data, enter the visit date.

- **Street Address (required):** Mother's current street address. If homeless, enter "Homeless".

- **Street Address 2:** Enter the mother's floor, apartment, suite, or any information that would not fit in the "Street Address" box. Otherwise, leave blank.

- **City (required):** Enter the City, Town, or Borough of the mother's current residence. If homeless, enter "Homeless".

- **State (required):** Select the abbreviation for the US State or Canadian Province of the mother's current residence; if the mother does not reside in the US or Canada, select "Out of Country". If homeless, select "NY".

- **ZIP Code (required):** Enter the US ZIP code of the mother's current residence. It must be a 5 or 9-digit number. If homeless, enter 99999. For a foreign country, enter 88888.

- **Hispanic:** Select the mother's ethnicity from the list: Hispanic, Not Hispanic, or Unknown. Answer separately from race. If the mother is both Hispanic and non-Hispanic, select Hispanic.

- **Race:** Select the mother's race from the list: White, Black (includes African American), Native American (includes American Indian or Alaskan Eskimo), Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, Other Asian, Pacific Islander, Other Race, or Unknown. This is to be answered separately from Hispanic. Race should be reported for Hispanic as well as non-Hispanic mothers.

Father's information

- **Father's Last Name:** Father's last name; may be hyphenated and include special characters such as apostrophes or periods. First name alone is not sufficient.

- **First Name:** Father's first name; may be hyphenated and include special characters such as apostrophes or periods

- **Middle Name:** Father's middle name or initial. Leave blank if unknown.

- **DOB (mm/dd/yyyy):** Father's date of birth with month, day and 4-digit year (for example, 12/31/1999). Please check admission sheet. This information is useful for birth certificate matching.

- **SSN:** The father's social security number. This number is used to facilitate birth certificate matching. Enter either 9 numbers (no hyphens) or the last four digits of the SSN.

Child's information

Last name (<u>required</u>): The child's last name as listed on the fetal death certificate or certificate of stillbirth. If the child is not named, enter the mother's last name. The last name may be hyphenated and include special characters such as apostrophes or periods.

Suffix: If the child has a suffix, select it from the drop-down menu. Otherwise, leave blank.

First name: Do not use "male/female child", "baby boy/girl", "B/G / B/B", or mother's first name. Please leave blank if child is not named.

Middle Name: The child's middle name or initial. Leave blank if unknown or the child is not named.

AKA/Other Name: Use this field for name(s) different from the child's last name listed above, for example, the mother's maiden name. The name may be hyphenated or contain special characters such as apostrophes or periods.

MRN: The medical record number assigned to the child by the hospital or office. It should not be more than 17 characters. Do not include dashes, spaces, or preceding zeroes. Leave blank if not assigned.

Gestational Age (weeks): Enter the completed weeks of gestation (e.g., if child was delivered at 37 weeks and 6 days, the completed weeks of gestation is 37 weeks).

Sex (<u>required</u>): Use drop-down button: Male, Female or Undesignated.

Plurality: Use drop-down button: Single birth, Twin, Triplet, Quadruple, Quintuple, Sextuple, or Other. Be sure to count all live and deceased births.

Birth Order: Use drop-down button: This field should be completed for multiple births only. Use drop-down screen to specify the order in which this child was born: 1st, 2nd, 3rd, 4th, 5th, or 6th. Be sure to count all live and deceased births.

Date of Delivery (<u>required</u>): The date the child was delivered with month, day, and 4-digit year using format of mmddyyyy or mm/dd/yyyy.

Birth Weight (grams): Report the child's weight in grams. The minimum weight for stillbirths is 250g. If unknown, leave blank. **Note: Some defects are only reportable if the child is over a certain birth weight**.

Diagnostic Information

ICD codes and birth defect descriptions **(required):** List valid ICD-10-CM codes and descriptions for all of the child's birth defects. For each ICD code, the specific diagnosis should be stated, not just the main term from the ICD code list. ***Non-specific diagnoses will be queried.*** All diagnosed conditions in the BDR *ICD-10 Reportable Congenital Malformations Coding Manual* should be reported. See examples below:

- If no defects, list "stillbirth" or "fetal death."
- If chromosomal or genetic defect is known, please specify the ICD code and description.
    - Examples of Genetic/Chromosomal birth defects:
        i. Q91.0- Trisomy 18, Edwards syndrome
        ii. Q91.7- Patau syndrome, NOS
    - If laboratory tests performed, specify the results under "Genetic Studies", or the testing laboratory name, if the results are still pending.
- Provide laterality if appropriate.
- If a specific syndrome is listed as the child's condition, include it in the list, along with all the associated anomalies.

Important: All Birth defect descriptions must be specific.

Genetic Studies: If chromosome studies were done, please report the karyotype in long Paris nomenclature. Also report the results of other genetic testing such as genetic sequencing and chromosomal microarray (CMA) tests. If genetic testing was done, but the results cannot be found in the record, please enter the name of the cytogenetic lab or testing facility. If genetic study results will be available in a short time, delay reporting until they are received.

Additional Information

Write any additional information you would like us to know, or any other comments you may have about this child.

Submitting a report:
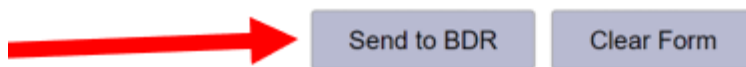
Remember to click on "Send to BDR" after completing data entry for each record!

When required information is missing such as Mother's name, address, date of delivery, sex, and date of discharge (or date of outpatient visit for healthcare providers), reports will be rejected and cannot be submitted at all. If you have difficulty with a submission because of missing information, please contact BDR staff at bdr@health.ny.gov.

A summary screen will appear when a report has been sent successfully to the BDR. When you view this information, if there are any errors, you can return to the prior screen and make corrections by clicking "Make Changes to this Report" found at the bottom right. Be sure to click "Send to BDR" after making changes. To enter another report, click "Enter Another Report".
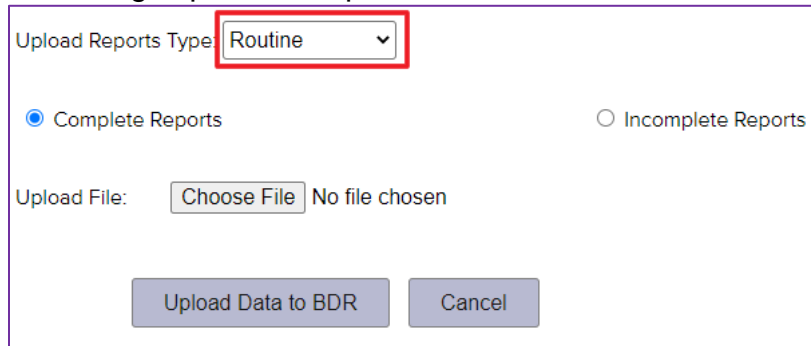
Upload Reports

To prepare a file for upload, a CSV file that contains the required information and has a <u>specific record layout</u> must be created (see

Appendix 1:). This is often done by the Information Technology (IT) department at a hospital. Once the file has been prepared, anyone with access to the BDR reporting application for a given hospital may upload the file.

How to Upload
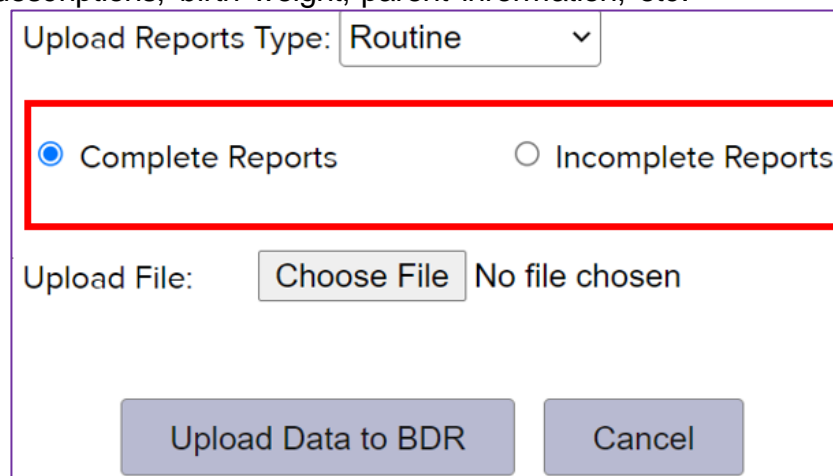
1. To upload the file, click on "Upload" from the menu.
2. Select report type from drop down menu. This will usually be "Routine". However, if you are submitting reports in response to a SPARCS audit, then select "SPARCS Audit" instead.

3. Choose whether the reports to be sent are **complete** or **incomplete**.
   a. <u>Complete Reports:</u> If your data system allows you to report all necessary data including a specific birth defect description, then click the "Complete Reports" button. If you click this, you should not need to reopen the unprocessed files to add birth defect descriptions.
   b. <u>Incomplete Reports:</u> If your file contains missing data or insufficient birth defect descriptions that have been retrieved directly from the medical record face sheet or attestation and therefore, are not specific enough for the BDR, then select the "Incomplete Reports" button. After the file has been uploaded to the BDR, someone from your hospital staff **must** open the unprocessed file and add the specific birth defect descriptions and any other missing information.

      We recommend selecting "Incomplete Reports" if you may have additional information to add/specify in the reports after the file has been uploaded (e.g., more specific birth defect descriptions, birth weight, parent information, etc.

4. Click on the "Choose File" button to browse to and select the file that will be uploaded to the BDR. Once you have selected the file, then click "Upload Data to BDR".

5. You will receive an acknowledgement if a file is uploaded successfully.
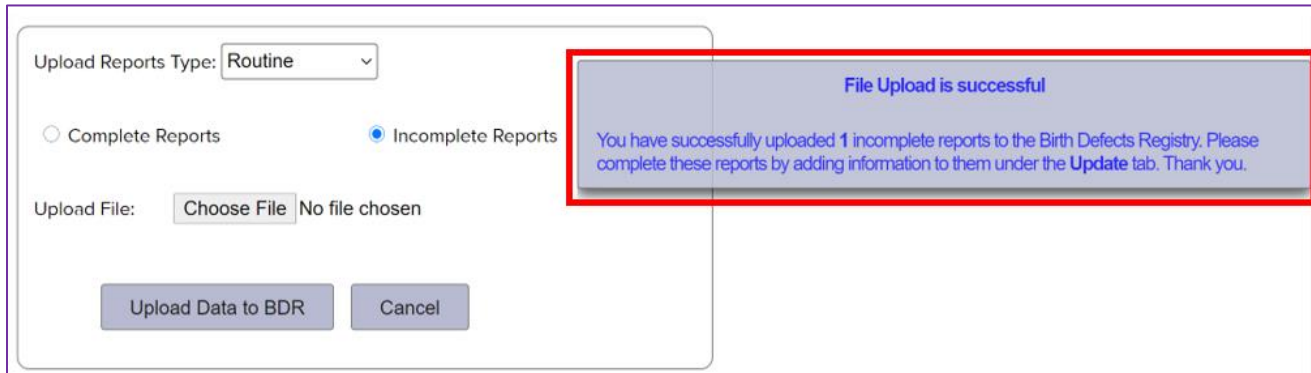
Failed Uploads

If the file was not successfully uploaded, then you will receive an error message. If this happens, please correct any issues noted in the error messages, and then try to submit the file again. If you continue to have difficulty with a submission, please contact the BDR at bdr@health.ny.gov.
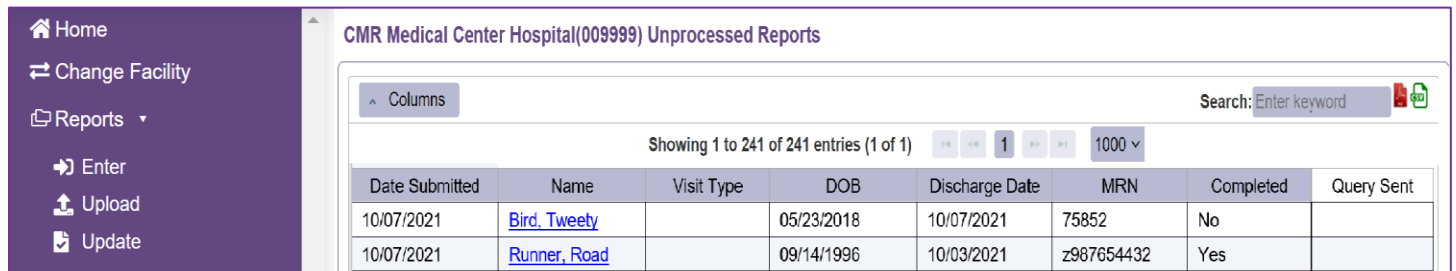
Finishing Uploads of Incomplete Reports

Incomplete submissions occur when a file is uploaded as "incomplete". This indicates that the reports within the file do not have all requested information from the medical record. **Incomplete uploaded reports must be updated.** After an incomplete file submission, hospital staff **must** do the following as soon as possible:

1. Navigate to "Reports", then "Update" in the left pane.
2. Find reports that have a "no" in the "completed" column. These are the incomplete reports.

3. Open each incomplete report by clicking on the child's name.
4. Add any missing/more specific information that is found in the medical record or chart.
5. Click "Submit Changes" to mark the incomplete report as complete.

   a. In the summary table on the "Update" screen, the column "Complete" will change from "No" to "Yes".

Update Reports

"Update" allows you to make changes to a report that is not yet processed by the BDR. If you have uploaded an incomplete file to the BDR, then this is the option you select to add missing information and more specificity to each report. "Update" was formerly called "Edit/View Unprocessed Case Reports". An "unprocessed" report is a record that your facility has submitted to the BDR but is still temporarily available for editing.

If you want to make changes in a report that is processed, you must do so by re-submitting the report or contacting the BDR at bdr@health.ny.gov.

Adding Information to Reports

1) Click on "**Update**". All reports that have a "No" in the "completed" column need to be worked

on.

2) Click on the name to open the report.

3) Review the report, particularly the codes and birth defect/birth outcome descriptions.

All descriptions that are not specific (they often contain language such as: "other specified congenital malformation of..."; "... unspecified"; "abnormality", etc.) need to be updated to the most specific birth defect diagnosis language available from the medical record. Make sure you clearly describe exactly what the child has. Descriptions such as "other specified congenital malformations of heart" are not specific enough for our purposes.

Any code for a chromosome-related anomaly needs to have the chromosome karyotype listed in the genetic studies section. These include ICD-10 codes Q56.4, and Q90-Q99. If the child was not born at your facility and you do not have the chromosome (karyotype, etc.) results, please include a note in the additional information box. For example, "child not born here, no chroms in chart."

Any requested information that is in the medical record but is not already in the report should be added (e.g., mother's information, child's full name, birth weight, etc.).

4) After you have reviewed the report, **make sure you click** "**Submit changes**", **even if you have not made any changes.** This will send the corrected or final report to the BDR as well as change the "no" in the "completed" field to a "yes."

If you discover that a report is not reportable to the BDR (for example: 1) a skin anomaly that is only a minor; 2) no longer a reportable condition, like phimosis; or 3) you have documentation that the child was born and resides outside of New York State), you can delete the report by clicking the "**delete**" button. This is permanent; you cannot retrieve the report once it has been deleted.

Queries

What is a Query?

A query is a **request for additional information** on a report that does not have enough detail for BDR staff to fully process the report. Someone from your hospital or healthcare facility must sign into the BDR application on the Health Commerce System to securely respond to queries. Responding to queries in a timely manner is extremely important for completing reports and allowing them to be fully processed within the Registry. Inadequate submissions result in queries. You may receive questions (queries) for the following reasons:

1. Lack of a specific birth defect diagnosis, such as:

    - Description with the terms:
        - congenital malformation of …
        - other congenital malformation of…
        - other specified
        - unspecified
    - Conditions missing laterality (applies to many of the musculoskeletal defects including congenital cataract, split earlobes, dislocation of hip, split foot, congenital shortening of lower limbs). Left, right or bilateral should be indicated.
    - Degree of severity missing- e.g., hypospadias.
2. Chromosomal results do not accompany the report of a chromosomal anomaly (applies to all chromosomal anomalies).
3. Child's birthweight is missing, and the birthweight is required to determine eligibility of the reported birth defect (e.g., patent ductus arteriosus, undescended testicles, etc.) or is needed for matching purposes
4. Any other field the BDR collects (e.g., parents' information) is missing

You can monitor, review, and respond to queries sent to your facility in the reporting application. Please respond with as much information as available **within 10 business days of receiving each query.** A continued lack of response or continued inadequate responses will be considered the same as not reporting.

Responding to Queries

Click on "Queries" from the left-hand menu of the BDR reporting application and a list of reports will come up. The number that appears in parentheses is the number of outstanding queries sent to your facility.

Your facility will not be credited with having sent the original report until the query is satisfactorily answered. Queries must be answered within 10 days of when they are sent to your facility.

📁 Reports ▾
➡ Enter
⬆ Upload
💾 Update
💬 Queries (3)
🏳 Audits ▾
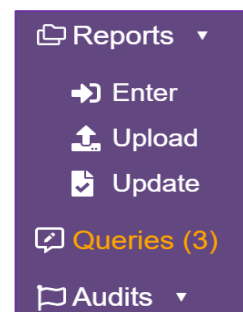
Click on each name to see the query.

Additional Information Requests sent to AMC- South Clinical Campus (000002)

Click the name to see the query.

Search: Enter keyword

Showing 1 to 3 of 3 entries (1 of 1) |◄ ◄ 1 ► ►| 1000 ▼

Sent ⇕	Name ▼	Query About ⇕	Visit Type ⇕	MRN ⇕	DOB ⇕	Discharge Date ⇕	Query Source ⇕	Query Topic ⇕
07/16/2020	Test, Boy	Child		34309	02/04/2020	02/14/2020	REPORTS	specify deformity
07/16/2020	Sfrdtg,	Child		123456	11/01/1900	06/02/2020	REPORTS	specify birth defect
08/10/2020	Fake, Girly	Child	Inpatient	999888777	04/01/2020	04/04/2020	REPORTS	Please provide mom's date of birth

Please **review the medical record** and answer the query in the "Response" box, then click on the "Send Response" button. Please also provide any additional information found in the chart but missing in the BDR report. BDR staff will add this additional information to the report in question.

BDR Information Request

Click the child's name to view the report.

PFI/Name:	AMC- South Clinical Campus (000002)	
Name:	Test, Boy	DOB:	02/04/2020
	Click Name to view/edit the report.		
MRN:	34309	Discharge Date:	02/14/2020
Last Query Sent:	07/16/2020	Birth Status:	Live birth

Please review the medical record when addressing the following request and include any missing information that was not originally provided.

Please specify the congenital anomoly listed as, All diagnoses listed as 'Anomoly of...'; NOS or NEC must be more specific.

specify deformity

Response:

Q35.1 Cleft hard palate

Respond here

Click when done → Send Response

Audits

About Audits

The BDR monitors hospital reports for completeness and accuracy. According to public health regulations, a child with a birth defect must be reported within 10 days of diagnosis by a hospital or physician. To make it less burdensome, children should be reported within 10 days of discharge from a hospital unless the facility submits reports through the monthly file upload process. When a child with a birth defect has not been reported within these time periods, the hospital is out of compliance. Reports that are lacking items necessary for processing will be considered incomplete. Queries resulting from incomplete reports must be answered within 10 business days.

The primary audit type currently being carried out is the BDR-SPARCS Comparison audit. Reporting hospitals are audited by comparing the BDR database to the SPARCS inpatient and outpatient databases for children who meet the age requirements with reportable ICD codes.

In addition, copies of medical records may be requested for specific reports previously reported to the BDR to validate accuracy and completeness of reporting.

We also monitor reporting compliance by tracking number of reports submitted by month and year, and observe timeliness of report submission.

Failure to comply with requirements to submit data to the BDR as mandated by Section 2733 of the Public Health Law may result in the State issuing your facility a Statement of Deficiency.

How to respond to a BDR-SPARCS Comparison Audit

Click on "Audits", then "SPARCS Comparison". A table will appear. Click on one of the numbers in the table.

A list of the medical records will appear. To respond to the audit:

1. Click on a hyperlinked child's MRN. A partially pre-filled form with information from SPARCS will automatically open.

2. Fill in as much information as possible from the medical record, including the ICD codes and birth defect descriptions. Provide any additional information as documented in the medical record.
3. Click "Send to BDR" in order to submit the report.
4. Repeat this process until all reports across all birth years are submitted, in order to complete the SPARCS audit.

SPARCS Audit Reports All, Birth Year 2010 PFI 009999

Below is information from SPARCS on reports that were not submitted to the Birth Defects Registry. Please click on Child's MRN or Mother's MRN to submit a report in response to this Audit

^ Columns   Search: Enter keyword

Showing 1 to 315 of 315 entries (1 of 1) |◄ ◄◄   1   ►► ►| 1000 ▾

Visit Type ⇕	Child's MRN ⇕	Mother's MRN ⇕	DOB ⇕	Admission Date ⇕	Discharge Date ⇕	Sex ⇕	Birth Weight (grams) ⇕	Birth Status ⇕	Diagnosis and Procedures ⇕
In	1002773261	1002773252	01/05/2010	01/05/2010	02/12/2010	M	2425	liveborn	745.5, 752.61, 753.29, 756.73
In	1002773519	1002773517	01/07/2010	01/07/2010	01/08/2010	M	3129	liveborn	745.10, 745.5, 747.0

Summaries

The Summaries tab provides 3 different types of reports to assist facilities in evaluating their own reporting.

Transactions

The transaction log shows who from your facility submitted reports and when. Under "Transaction Type", you can see if and when reports were: 1) added; 2) updated; 3) deleted because the defect was not reportable for the given birthweight, or sex; 4) deleted because they were a minor birth defect **without** a major defect; 5) deleted because they were a duplicate report; or 6) deleted for other reasons. This will allow you to keep track of any report, even those that have already been processed.

ⓘ Summaries ▾

👤✓ Transactions

🏷 Report Card

📊 Reports by Year

Search: Enter keyword
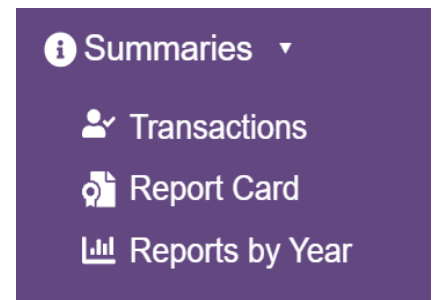
Showing 1 to 63 of 63 entries (1 of 1) |◄ ◄◄   1   ►► ►| 1000 ▾

Transaction Date ⇕	Transaction Type ⇕	Report ID ⇕	User ID ⇕	Visit Type ⇕	Name ⇕	DOB ⇕	Discharge Date ⇕	MRN ⇕	Date Submitted ⇕
07/23/2020	Added	R0000022020000112	anl03		Fake, Girl	04/02/2020	04/04/2020	736518	07/23/2020

Report Card

The Report Card provides an overview of a facility's reporting status as well as the quality and completeness of the reports submitted. Some of the statistics displayed include the average number of days between discharge date and date of reports sent to BDR for a given period, reasons for reports being deleted by BDR, query responsiveness, and completeness percentages for select fields.

The report card is not currently active in the reporting application; however, you may submit a request for BDR staff to generate one for your facility. To select criteria to share when requesting a Report

Card for your facility, click on "Summaries", then "Report Card". Select the report monitoring period (start and end discharge dates, and time between discharge and date reported) that you would like to view, then email us at bdr@health.ny.gov with your hospital name, PFI, and the criteria you're looking for in the report card. The BDR team will then generate the report and send it by email.

Table 1. Reporting Status

Category	Reports This Period (11/08/2021 - 1/26/2022)(a)	Previous Number of Reports (11/08/2020-1/26/2021)(a)
Reports by Discharge Month		
January	0	38
November	28	57
December	19	71
Total Reports	47	166
Reasons Reports Were Deleted (b)		
Duplicate report	5	1
Diagnosis not reportable (c)	2	3
Not reportable due to birth weight or sex	3	1
Not born or living in NYS	0	0
Only minor birth defect(s) reported without major birth defect(s)	2	16
PFO not ASD	0	1
Other	0	0
Unknown	0	0
Total Deleted	12	22
Queries Sent (d)		
Completed	7	30
Deleted	0	0
Responded	0	0
Unresolved	1	3
Total Queries	8	33

(a) If the time period selected is greater than one year, the number of reports will be an average.
(b) The BDR Staff routinely delete reports that do not meet the reporting criteria. (c) The reported diagnosis is not reportable to the BDR.
(d) Queries are specific questions sent to your facility about a specific report, usually asking for more specific information, chromosomal results, correction of data, etc.

Table 2. The completeness of reporting of selected data

Information Requested	Time Period Selected (11/08/2021 - 1/26/2022) % (b)	Previous (11/08/2020-1/26/2021)% (b)	Status(c)
Newborn Information (a)			
Birth Order	14.0	12.5	n/c
Birth Status	100.0	100.0	n/c
Birth Weight	100.0	100.0	n/c
Mother's MRN	96.5	0.0	★
Plurality	100.0	100.0	n/c
Pulse Ox Screening	59.6	50.0	★
Child's Information			
Born at This Facility	100.0	100.0	n/c
Ethnicity	99.1	93.5	★
First Name	100.0	99.4	n/c
Race	100.0	100.0	n/c
Mother's Information			
Date of Birth	66.1	47.0	★
Last Name	97.3	92.3	★
Maiden Name	21.4	13.7	★
SSN	55.4	41.7	★
Father's Information			
Last Name	83.0	53.0	★

(a) Percentages based on reports of newborns born at your facility
(b) Percent of reports that have values
(c) ✗=getting worse, n/c=no change, ★=getting better
The red highlight indicates the value is 0%
The yellow highlight indicates the value is below 85%

Reports by Year

The Reports by Year summary allows a facility to view the number of reports submitted by year and compare to previous years based on the year of discharge. This is not currently available in the reporting application, however the BDR team can produce this report for you. To request a report, please email us at bdr@health.ny.gov with your hospital name, PFI, and the discharge year or range of years you are interested in.

Number of Discharges for CMR Medical Center Hospital (PFI=009999) by Year
Data retreived on October 20, 2021

Visit Type	2019	2020	2021	2018	Total
Missing	27	61	22	5	115
Inpatient	5	4	1	0	10
Outpatient	7	0	0	0	7
Other	1	0	0	1	2
Total	40	65	23	6	134

Search

Search allows you to find reports that have been submitted by your facility. Click on "Search" and the "Search for Reports" screen will open. To see all your reports, click "Search". To find a particular report or group of reports, fill in one or more of the boxes and then click "Search". Leave any field blank that is not needed. For example, you can search for any report using last name or medical record number.

Search for Reports

Enter information in the fields you wish to search on and click Search. For example, if you want to find all reports submitted in 2019 where child's last name started with 'SM', select '2019' from the Date Submitted Year dropdown menu, type 'SM' in Child's Last Name field, then click Search.

Date Submitted - Month:	[▾]	**Day:**	[▾]	**Year:**	[▾]
PFI:	009999 : CMR Test Hospital			**Report ID:**	[ ]
User ID:	[ ]	**Child's MRN:**	[ ]	**Report Type:**	[▾]
Child's Last Name:	[ ]	**Birth Status:**	[▾]	**Mother's Last Name:**	[ ]
Child's First Name:	[ ]	**ZIP Code:**	[ ]	**Mother's First Name:**	[ ]
Child's DOB - Month:	[▾]	**Day:**	[▾]	**Year:**	[▾]
Mother's DOB - Month:	[▾]	**Day:**	[▾]	**Year:**	[yyyy]
Birth Weight (grams):	[ ]	**Child's Sex:**	[▾]	**Mother's MRN:**	[ ]
Discharge Date - Month:	[▾]	**Day:**	[▾]	**Year:**	[▾]
Plurality:	[▾]	**ICD Code:**	[ ]		
Description:	[ ]				
Start Birth Year:	[▾]	**End Birth Year:**	[▾]		

[Search] [Clear Form]

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Hospital Contacts

Please review your facility's contact information ("Hospital Contacts") regularly (at least twice a year and every time you lose or gain staff) and update it as needed. This information includes the name and address of your facility and the names and contact information for various staff/roles. You must click "Save" at the bottom of the screen to save any updates.

General Information

PFI Number:	009999		HANYS Affiliated:	○ Yes	● No

Last Updated:	08/10/2020	Software:	

Hospital Name:	CMR Test Hospital

Street Address:	547 River Street	City:	

State:	NY	ZIP Code:	121802216

Perinatal Level:		Operator:	

Service Type(s):

☐ NICU ☐ Maternal ☐ ED ☐ Pediatric ☐ Neonatal

The contact information will be used by BDR staff to send reporting reminders and information about training opportunities.

Contacts

⌃ Columns

Showing 1 to 3 of 3 entries (1 of 1) |◀ ◀◀ **1** ▶▶ ▶| 1000 ⌄

Role	First Name	Last Name	Department	Title	Phone Number	Extension	Email Address	Preferred Contact Method	
BDR Rec ⌄	Amanda	St. Louis	Cmr	Deputy Dire	518402795		amanda.st.l	Email ⌄	🗑
Director ⌄	Michele	Herdt	Cmr	Director	518402795		michele.her	Email ⌄	🗑
Release ⌄	New_test	New_test		New Testing	518402795			Email ⌄	🗑

➕

Save

Help

The help option contains various resources that are helpful to BDR reporters.

Reportable ICD codes

This section opens the *NYS BDR ICD-10 Reportable Congenital Malformations Coding Manual: List of all Reportable Malformations* (PDF). This document explains which birth defects are reportable.

Handbook

This section opens this document, the *Birth Defects Registry (BDR) Handbook: Reporting Guidance for Hospitals and Healthcare Facilities* (PDF).

Training Material

This section contains various training videos developed by BDR staff. They include information on the BDR, various groups of births defects, and reporting to the registry.

Additional Resources

This section will have additional documents relevant to Birth Defect Registry operations added as needed.

Contact BDR

This page contains the BDR's address, phone/fax numbers and email. If you wish to send a comment, concern, or question, please click on the e-mail address.
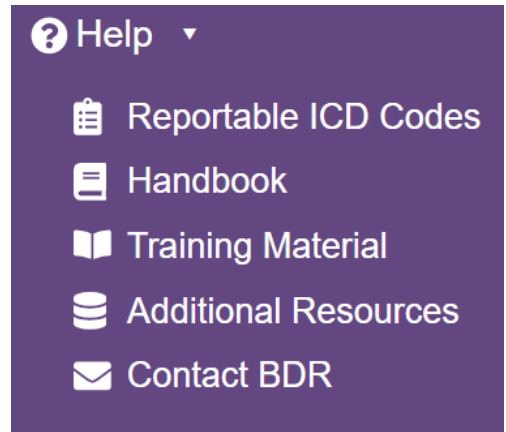
Appendix 1: File Upload Record Layout & Description of Variables

Requirements and Updates:

- **CSV** is the only acceptable file format for uploads. Files with byte order mark (BOM) will be rejected.
- The full header line is required.
- Enclose text strings in double quotes. Numbers do not need quotes. Separate all values by commas. Use prescribed order.
  - Modified for new application 2021.
  - Added fields: visit_type, nbscreenid2, nbscreenid3, and mMRN
- Updated value assignment: hispanic, cSex
- Fields specified as **Required** are the <u>bare minimum</u> for the file upload to be accepted as complete. The expectation is that you will include **ALL available fields** from the medical record.

Name in header line	Order	Maximum characters allowed	Description
pfi	1	6	**Required**. The permanent facility identifier (PFI) number of your hospital. 6 digits.
MRN	2	17	**Required for live born**. Child's Medical Record Number
Visit_type	2a	1	Patient visit type: I=inpatient, O=outpatient, or X=other (new)
cLast	3	40	**Required**. Child's Last Name. If not available for non-live born, use mother's last name.
cSuffix	4	6	Suffix of Child's last name. Ex. "Jr.", "2nd", etc.
cFirst	5	30	Child's First name
cMiddle	6	30	Child's Middle Name
cAKA	7	20	Other name the child is known by
cAddress1	8	36	**Required.** Child's address line 1 for live born or Mother's address line 1 for non-live born. Follow US/Canada Post Office specifications.
cAddress2	9	36	Child's address line 2 for live born or Mother's address line 2 for non-live born.
cCity	10	40	**Required.** Child's city for live born or Mother's city for non-live born.
cState	11	4	**Required.** Child's state for live born Mother's state for non-live born.
cZIP	12	9	**Required.** Child's ZIP or Mother's ZIP for non-live born. No hyphens. US ZIP codes should be 5 or 9 digits.
cDOB	13	8	**Required.** Child's date of birth, or date of delivery for non-live born. Use format yyyymmdd.
BirthStatus	14	1	**Required**. Birth status code. 1=Live birth, 2=Stillbirth, 3=Other Non-liveborn (updated values)
gestweek	15	2	Weeks of gestation
Birthweight	16	4	Child's birth weight (grams)
cSex	17	1	**Required.** Child's sex. M=male, F=female, U=unknown/undesignated (updated values)
cRace	18	2	Child's race. 01=White, 02=African American, 03=Native American, 41=Asian Indian, 42=Chinese, 43=Filipino, 44=Japanese, 45=Korean, 46=Vietnamese, 49=Other Asian, 5X=Pacific Islander, 88=Other Race, MR=Multi-Racial, 99=unknown
hispanic	19	1	Hispanic. 1=Hispanic, 0=Non-Hispanic, 9= Unknown (updated values)
Plurality	20	1	Multiple birth: 1=Single birth, 2=Twin, 3=Triplet, 4=Quadruple, 5=Quintuplet, 6=Sextuplet, 9=Other
birthorder	21	1	Birth order: 1=1st, 2=2nd, 3=3rd, etc.

Name in header line	Order	Maximum characters allowed	Description
bornhere	22	1	Born at this facility code. 0=unknown, 1=Yes, 2=No.
birthplacePFI	23	6	6-digit PFI of birth hospital, 009990=unknown NYS hospital, 009991=hospital outside NY state, 009992=not born in a hospital
Discharge_date	24	8	**Required.** Discharge date. Use format yyyymmdd (of the child for live born, of the mother for non-live born)
DeadYN	25	1	Child's Deceased indicator. Blank=Unknown, Y=Yes, N=No.
Death_date	26	8	Child's date of death. Use format yyyymmdd.
Fost_Adopt	27	1	Fostered or adopted code. 0=missing, 1=Foster, 2=Adopted, 3=No.
Icd10_1	28	7	**Required.** 1st ICD-10 diagnosis code. Must start with a letter. Omit decimal point.
Icd10_2	29	7	**Conditionally required*** 2nd ICD-10 code. Must start with a letter. Omit decimal point.
Icd10_3	30	7	**Conditionally required*** 3rd ICD-10 code. Must start with a letter. Omit decimal point.
icd10_4	31	7	**Conditionally required*** 4th ICD-10 code. Must start with a letter. Omit decimal point.
icd10_5	32	7	**Conditionally required*** 5th ICD-10 code. Must start with a letter. Omit decimal point.
icd10_6	33	7	**Conditionally required*** 6th ICD-10 code. Must start with a letter. Omit decimal point.
icd10_7	34	7	**Conditionally required*** 7th ICD-10 code. Must start with a letter. Omit decimal point.
icd10_8	35	7	**Conditionally required*** 8th ICD-10 code. Must start with a letter. Omit decimal point.
icd10_9	36	7	**Conditionally required*** 9th ICD-10 code. Must start with a letter. Omit decimal point.
icd10_10	37	7	**Conditionally required*** 10th ICD-10 code. Must start with a letter. Omit decimal point.
icd10_11	38	7	**Conditionally required*** 11th ICD-10 code. Must start with a letter. Omit decimal point.
icd10_12	39	7	**Conditionally required*** 12th ICD-10 code. Must start with a letter. Omit decimal point.
narra1	40	165	**Required**. 1st specific description of the birth defect
narra2	41	165	**Conditionally required*** 2nd specific description of the birth defect
narra3	42	165	**Conditionally required*** 3rd specific description of the birth defect
narra4	43	165	**Conditionally required*** 4th specific description of the birth defect
narra5	44	165	**Conditionally required*** 5th specific description of the birth defect
narra6	45	165	**Conditionally required*** 6th specific description of the birth defect
narra7	46	165	**Conditionally required*** 7th specific description of the birth defect
narra8	47	165	**Conditionally required*** 8th specific description of the birth defect
narra9	48	165	**Conditionally required*** 9th specific description of the birth defect
narra10	49	165	**Conditionally required*** 10th specific description of the birth defect
narra11	50	165	**Conditionally required*** 11th specific description of the birth defect
narra12	51	165	**Conditionally required*** 12th specific description of the birth defect
karyotype	52	55	Karyotype/results of chromosome studies
cytolab	53	55	Name of cytogenic lab
Nbscreenid1	54	12	Child's newborn screening ID number
nbscreenid2	54b	12	Child's newborn screening ID number (new)
nbscreenid3	54c	12	Child's newborn screening ID number (new)

Name in header line	Order	Maximum characters allowed	Description
PulseoxYN	55	1	Pulse oximetry screening indicator. 0=Missing, 1=Yes, 2=No, 3=Refused, 9=Undetermined.
Pulseox_date	56	8	Date of pulse oximetry testing. Use format yyyymmdd.
PulseoxPF	57	1	Pulse oximetry screening result. 1=pass, 0=fail
Pulseoxh1	58	4	% saturation, 1st pulse-ox screening of hand
Pulseoxf1	59	4	% saturation, 1st pulse-ox screening of foot
Pulseoxh2	60	4	% saturation, 2nd pulse-ox screening of hand
Pulseoxf2	61	4	% saturation, 2nd pulse-ox screening of foot
Pulseoxh3	62	4	% saturation, 3rd pulse-ox screening of hand
Pulseoxf3	63	4	% saturation, 3rd pulse-ox screening of foot
mLast	64	40	**Required for non-live born.** Mother's last name
mFirst	65	30	**Required for non-live born**. Mother's first name
mMiddle	66	30	Mother's middle name
mMaiden	67	35	Mother's maiden name
mPhone	68	20	Mother's phone number
mDOB	69	8	**Required for non-live born.** Mother's date of birth. Use format yyyymmdd.
mMRN	69a	17	**Required for non-live born.** Mother's medical record number (new)
mssn	70	9	Mother's SSN. Do not include hyphens
flast	71	40	Father's last name
ffirst	72	30	Father's first name
fMiddle	73	30	Father's middle name
fDOB	74	8	Father's date of birth. Use format yyyymmdd
fssn	75	9	Father's social security number. Do not include hyphens.
pLast	76	40	Child's primary care provider's last name
pFirst	77	30	Child's primary care provider's first name
plicense_type	78	2	Child's primary care provider's license type (click link for list)
plicense	79	6	Child's primary care provider's license number
pAddress1	80	100	Child's primary care provider's address line 1
pAddress2	81	78	Child's primary care provider's address line 2
pCity	82	40	Child's primary care provider's city
pState	83	4	Child's primary care provider's state
pZIP	84	9	Child's primary care provider's ZIP code
pPhone	85	20	Child's primary care provider's phone number
ICD9_1	86	6	1st ICD-9 code. Do not include decimal point (e.g., 758.0 as 7580). Include leading zeros if present (e.g., 90.0 as 0900).
ICD9_2	87	6	2nd ICD-9 code. Do not include decimal point. Include leading zeros if present.
ICD9_3	88	6	3rd ICD-9 code. Do not include decimal point. Include leading zeros if present.

Name in header line	Order	Maximum characters allowed	Description
ICD9_4	89	6	4th ICD-9 code. Do not include decimal point. Include leading zeros if present.
ICD9_5	90	6	5th ICD-9 code. Do not include decimal point. Include leading zeros if present.
ICD9_6	91	6	6th ICD-9 code. Do not include decimal point. Include leading zeros if present.
ICD9_7	92	6	7th ICD-9 code. Do not include decimal point. Include leading zeros if present.
ICD9_8	93	6	8th ICD-9 Code. Do not include decimal point. Include leading zeros if present.
ICD9_9	94	6	9th ICD-9 code. Do not include decimal point. Include leading zeros if present.
ICD9_10	95	6	10th ICD-9 code. Do not include decimal point. Include leading zeros if present.
ICD9_11	96	6	11th ICD-9 code. Do not include decimal point. Include leading zeros if present.
ICD9_12	97	6	12th ICD-9 code. Do not include decimal point. Include leading zeros if present.
More_info	98	255	Any additional information you would like us to know (formerly labelled 'narrative')

*ICD codes are required if a corresponding description is present; descriptions are required if a corresponding ICD code is present.

Healthcare Provider's License Type Codes (plicense_type)

Code	Description
10	Licensed Practical Nursing (LPN)
11	Medical Physicist, medical health
22	Nurse, RN
23	Physician Assistant
33	Nurse Practitioner, Family Health
35	Nurse Practitioner, Neonatology
36	Nurse Practitioner, Obstetrics and Gynecology
38	Midwife
39	Nurse -Practitioner, Perinatology
43	Nurse -Practitioner, Acute care
60	Physician
61	Physician with 3-year limited license

Appendix 2: Frequently Asked Questions

Who Should Report/When to Report

Q: My facility no longer delivers babies; do we have to report to the BDR?

A: If your facility continues to treat children 10 years of age or younger, then you must submit reports of birth defects or non-liveborn outcomes to the BDR.

Q: A child was born at our facility, but his parents live in New Jersey, do we have to report his birth defect?

A: Yes, if a child is either born or lives in New York State, then they must be reported to the New York State BDR.

Q: A child was not born at our facility, but was born in NYS or resides in NYS, do we have to report his birth defect?

A: Yes, all hospitals in NYS are required to report any new birth defect diagnosis for a child who was either born in NYS or who lived in NYS before they were 2 years of age, regardless of their birth hospital.

Q: This child has had several admissions to our facility; do we need to report the child to the BDR each time s/he is admitted?

A: A child with a specific birth defect must be reported after they're diagnosed or first seen at your facility. If, on subsequent admissions, the child is being treated for that same defect and no others, then you do not need to report that child again. However, if additional birth defects are diagnosed, then the child must be reported again and each time a new diagnosis of a birth defect is made. Previously reported birth defects for the child should not be reported again.

Q: A child was just admitted who was transferred from another facility. That facility reported the birth defect to you, do we have to report the child also?

A: Yes, every facility that treats a child with a birth defect must send in a report for that child regardless of where else the child has been treated.

Q: My hospital/healthcare facility has not submitted birth defects report before, but we have some to report. Can we report?

A: Yes, you can. Please see sections on requesting HCS access and online reporting. If you experience any difficulty, and/or would like to set up a training for your team, please email bdr@health.ny.gov for assistance.

Q: How long from the date of discharge do I have to report a child to the BDR?

A: According to public health regulations, a child with a birth defect must be reported within 10 days (of diagnosis) by a hospital or physician. To make reporting less burdensome, children should be reported within 30 days of discharge from a hospital. When a child with a birth defect has not been reported within these time periods, the hospital is out of compliance.

Q: Do laboratories have to report to the Registry?

A: Laboratories are required to report positive results indicating presence of a genetic or chromosomal birth defect to New York State. For example, a laboratory result confirming a diagnosis of Trisomy 21, Down syndrome needs to be reported. These results are reported electronically through the NYSDOH's Electronic Clinical Laboratory Reporting System (ECLRS).

Q: Is a child reportable if there is no real address information and hospital of birth is unknown?

A: Yes, the child is reportable. Enter street address: Unknown; City: Unknown; State: blank; ZIP 99999

How to Report

Q: How does our new employee obtain access to the Health Commerce System to report to the BDR?

A: Refer to the "Where do I register?" section.

Q: How do I report if my hospital merged with another hospital?

A: Each hospital with a permanent facility identification (PFI) number should continue to report under its own PFI number. If you need access to the BDR to report for another hospital, please refer to the requesting BDR access section.

Q: If my healthcare organization is reporting for several different facilities with different PFI numbers, can reporting be done under just one PFI or must the PFI numbers reflect the location where the patient with a birth defect was seen?

A: The PFI number for a respective patient with a birth defect should reflect the facility that provided the care to allow effective monitoring of reporting timeliness and completeness.

Q: I'm having trouble reporting in the HCS, but my colleague's account works fine. Is it okay if I use theirs?

A: It is important that you log into the HCS as yourself when reporting to the BDR. Do not report under someone else's name. Instead, please contact us at bdr@health.ny.gov if you are having issues and if we can't resolve the problem, we will point you to someone who can help.

Entering a BDR report

Q: When submitting a routine confidential report to the BDR, should we fill out everything or just the fields which are mandatory?

A: We ask that you fill out as many fields as possible based on information in the medical record. We realize that there are circumstances where you may not have all the information. For example, if the child was not born at your hospital, you may not have the child's birth weight. Complete reporting is important for quality data.

Q: If a child has a corrected birth defect, does the child still need to be reported to the BDR? For example, the child had orchidopexy and urethroscopy for undescended testis Q53.10 and the child's birth weight was over 2,500 grams.

A: Yes, the child needs to be reported to the BDR. Corrective surgery is often an indication of a major birth defect. All major defects are reportable to the BDR.

Q: I am responding to a SPARCS Comparison Audit or a Hospital Discharge Audit. Can I use the most current address for the patient, or do I have to search for the one related to the date of discharge?

A: You may use the most current address for the child.

Q: I only have father's phone number, not mother's phone number. Can I enter father's phone number in the mother's phone number field when entering a report?

A: No. Please only enter the mother's phone number in the mother's phone number field.

Q: How do I enter the child's address if it says, "Child of a Diplomat"?

A: Please make every effort to find and enter the local, temporary address. In the absence of that, a billing address if within the United States. If nothing else is available, Street address: Child of Diplomat; City: Unknown; State: Out of Country; ZIP 99999

Q: How do I enter the child's address if it is unknown or listed as the hospital's address?

A: Street address: Unknown; City: Unknown; State: NY; ZIP 99999

Q: How do I enter the child's address if it says "Homeless"

A: Street address: Homeless; City: Homeless; State: NY; ZIP 99999

Q: Should the address be entered as the current address or address at the time of service?

A: Please enter the current address.

Using Secure File Transfer

Q: If I send a file by Secure File Transfer, does it count as reporting to the BDR?

A: No, Secure File Transfer is used as a troubleshooting tool to share confidential information and is not a means for reporting to the BDR.

Q: Can I submit routine reports via Secure File Transfer?

A: Routine reports should be submitted using the BDR reporting application on the HCS.

Q: Is sending SPARCS audit reports via the Secure File Transfer the same as reporting them?

A: SPARCS audit reports should be submitted via the BDR reporting application on the HCS under **Audits** then **SPARCS Comparison.** If you have a question about specific SPARCS audit reports, please contact a BDR staff person, who will help answer your question.

Q: Who should I send files to when I use Secure File Transfer?

A: Please send your correspondences to a BDR staff person using their User ID to find their name. For example, if you are sending a file to Alicia Lee, search for her User ID (anl03),). Other User IDs for BDR staff are Amanda St. Louis (axs39), Gwen LaSelva (gdb02), Laura Brady (lsb04), Cindy Link (cmb11), Douglas Done (dhd01), Adrian Michalski (amm24), and Brittany Casale (bsc03).

To find the name of the person you are sending a file to, click on the address book icon, type in their User ID, and then click the magnifying glass. Select the name of the person you are looking for and then click "Send To…". If you don't know the User ID, click on the address book icon and type in the first or last name of the person you are sending a file to.

Non-liveborn Reporting

Q: What is the difference between a stillbirth and other non-live born?

A: A stillbirth is defined as a spontaneous intrauterine fetal death occurring at 20 or more weeks of gestation or 350 or more grams delivery weight with unknown gestational age. Other non-livebirths are fetal deaths prior to 20 weeks gestation, such as spontaneous abortion or miscarriage, or terminations at any gestational age.

Q: What will be done with non-live born reports?

They will be used to understand how often stillbirths and other non-livebirths occur, how frequently they are associated with birth defects, and what the risk factors may be that result in these birth outcomes.

Q: The child that is to be reported was non-liveborn, however there is insufficient information in the chart to determine gestational age. How do I select Birth Status?

If the child was non-liveborn, and you do not have the gestational age to determine if the birth status was Stillbirth or other non-liveborn, please select other non-liveborn.

Q: If I report a stillbirth or other non-livebirth, after selecting the birth status, do I need to list the ICD10 code and birth status description (e.g., IUFD) in the ICD 10 Description section?

A: Yes. We need to see the code and description in order to confirm the birth outcome. We will send a query asking for more information if you do not provide this level of detail.

Q: Why do we need to report non-live births to the Registry?

A: Stillbirth is a much under-studied birth outcome and results in considerable emotional and psychological impact for affected families. There is very limited population-based surveillance data. Birth defects surveillance systems are a useful tool because: 1) they have an established surveillance mechanism; and 2) provide more complete information on the occurrence of birth defects**.**

BDR Terminology

Q: What is a Statement of Deficiency?

A: It is a legal document issued by the State that describes how the facility was out of compliance with New York State Rules and Regulations. In response to the Statement of Deficiency, the facility must submit a Plan of Correction that details the corrective action the facility will implement to prevent such occurrences in the future.

Appendix 3: Using the Secure File Transfer 2.0 Utility on the Health Commerce System

Facilities can use the Secure File Transfer 2.0 (SFT 2.0) Utility to send files or messages that contain confidential information, such as medical records. In general, the BDR reporting application is mostly used to submit Routine Reports and SPARCS Comparison Audit reports. For complete instructions on using SFT 2.0, please click here Secure File Transfer 2.0 .

Secure File Transfer 2.0 Instructions & Information

Launch the Secure File Transfer 2.0

NEW! The Secure File Transfer utility has a new look and feel.
Secure File Transfer 2.0 (SFT) is a utility that provides solutions for the handling of sensitive information, including financial files, medical records, legal documents, personal data, etc. SFT securely collects, stores, manages, and distributes information between the NYS Health Commerce System (HCS) users. The utility will securely and easily transfer files and folders of up to 2GB in size between two or more users. It uses email addresses from the HCS Communications Directory to send and receive packages. This utility is similar to your email system. It has an Inbox, Drafts, Sent, Templates and Trash mailboxes. For more information, please view the Secure File Transfer 2.0 Quick Reference Guide.

I want to...

Register (only once)
- Click the Launch the Secure File Transfer 2.0 button. By clicking the button, the utility recognizes you as a user. That is it, you are registered! Now other user's of the SFT can find you in the system and send you a file.

The Secure File Transfer 2.0 (SFT 2.0) Utility on HCS can be used to send files or messages that contain confidential information, such as medical records or protected health information. The BDR reporting application must be used to submit Routine Reports, SPARCS Comparison Audit Reports, and other report types. SFT 2.0 should only be used for sharing confidential information with BDR staff outside of routine reporting.

For instructions on how to access and use SFT 2.0, Click here - Secure File Transfer 2.0 Reference Guide.

How to access Secure File Transfer 2.0
1. Log on **HCS** (https://commerce.health.state.ny.us)
2. Click on **"My Content"** located in the upper right of the menu bar
3. Click **"All Applications"**
4. Click on **"S"** in the alphabet and click **"Secure File Transfer 2.0"**
   a. To add a shortcut, look in the last column and click the green circle with the white plus sign image

Health Commerce System Applications

Browse by A B C D E F G H I J K L M N O P Q R **S** T

Application Name
Safe Drinking Water Information System
School Survey (HERDS)
Search for E-mail Address/Phone Number (System Account Information)
Secure Collaboration
Secure File Transfer 2.0