

Environmental Public Health Tracking and Birth Defects Surveillance in Florida

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Environmental Public Health Tracking

Public Health Importance In Florida

- 2008 FL Population Estimates – 18,895,559
 - <1-19 years of age (2007) 3,495,473
 - 50-85+ years of age (2007) 6,814,620
 - Total for these 2 age groups 10,310,093
- 2007 Florida Resident Births 239,120
 - 2006 FBDR Data (major birth defects) 8,769



Florida Environmental Hazard Facts

- Toxic Release Inventory (2002) 735
- NPL (or Superfund) sites (2009) 52
- Dry cleaner facilities (2009) 5,367
- Petroleum contaminated sites (2004) 23,102
- Landfills & Solid Waste Facilities (2009) 2,756



Florida EPHT Web Portal

Department of Health
 Division of Environmental Health
[Secure Login for Researchers](#)
[Home](#)

Environmental Exposure

- [Air Quality](#)
- [Drinking Water](#)

Health Effects

- [Asthma](#)
- [Birth Defects](#)
- [Carbon Monoxide Poisoning](#)
- [Lead Poisoning](#)
- [Heart Attacks](#)

Florida's Population

- [Census](#)

Glossary:
[CDC glossary](#)
[DCEPA terms](#)

Training:
[EPHT 101](#)

Contact Us:
eh_tracking@doh.state.fl.us

In cooperation with the Centers for Disease Control and Prevention (CDC), the Florida Environmental Public Health Tracking (EPHT) Program created this web portal to improve environmental health surveillance to better identify and mitigate public health effects resulting from environmental exposures.

Environmental Exposure	Health Effects	Florida's Population
Air Quality	Asthma	Census
Drinking Water	Birth Defects	Carbon Monoxide Poisoning
	Lead Poisoning	Heart Attacks

National Environmental Public Health Tracking Program

Tracks 2009: The Future of Environmental Public Health
 Join us in Washington DC, Feb 24-26th.
[More...](#)

Journal of Public Health Management and Practice: Tracking Edition.
 The November-December 2008 issue of the Journal of Public Health Management and Practice (JPHMP) is devoted entirely to environmental public health tracking.
[More...](#)

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12 Different Birth Defect Indicators

- Poisoning
- Lead Poisoning
- Heart Attacks
- Florida's Population**
- Census

Defects are unknown. The public remains concerned about the role of our environment and birth defects, but few exposures have been well studied.

Birth defects are one of the leading causes of infant deaths, and babies born with birth defects have a greater chance of illness and long term disability. The cost of lifetime care for infants born in a single year with one or more of 17 severe birth defects has been estimated at \$6 billion.



FAQ
What can I do to help have a healthy pregnancy and a healthy baby?
Why are we concerned about environmental hazards and what is known about birth defects?
How will CDC and Florida EPHT be tracking birth defects?
[more...](#)

To see indicator data, please select indicator


Number of live births with Anencephaly

Links to other websites:

- [March of Dimes](#)
- [Florida Birth Defects Registry](#)
- [Bureau of Environmental Public Health Medicine](#)
- [Preventing Birth Defects](#)
- [Having a Healthy Pregnancy](#)

[Home](#) | [National Health Tracking Portal](#)

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Birth Defects Surveillance Program @ the University of South Florida

- Partners with the Florida Department of Health (FDOH) to engage in birth defects surveillance activities
 - Case ascertainment
 - Epidemiology
 - Planning/Prevention
 - Educational/Social
 - Healthcare and human services
 - Clinical
- Primary projects through FDOH
 - Florida Birth Defects Registry (FBDR)
 - CDC-funded Active Surveillance Project
 - Environmental Public Health Tracking (EPHT)



Birth Defects Surveillance Activities

- **Passive** case ascertainment
 - Florida Birth Defects Registry
 - Statewide population-based registry, since 1999
- **Active** case ascertainment
 - CDC Active Surveillance Project
 - NCBDDD CDC cooperative agreement, since 2003
 - Environmental Public Health Tracking
 - NCEH CDC cooperative agreement, since 2007



Environmental Public Health Tracking

Birth Defects Surveillance Needs

- **Prevalence of selected birth defects** for use on the National Public Portal
 - Estimates using statewide passive registry (FBDR)
- **Diagnosis confirmation**
- **Detailed data abstracted** from hospital records on specific maternal and infant conditions
 - Construct catchment area and use active case-finding



Florida Birth Defects Registry



Florida Birth Defects Registry

- **Statewide** surveillance registry created in 1998
 - **Passive** case ascertainment methodology
 - **FBDR inclusion criteria**
 - Infant born alive
 - Mother resident of Florida at time of child's birth
 - Birth defect covered by the FBDR
 - includes major anomalies recommended by the National Birth Defects Prevention Network (NBDPN)
- Diagnosis prior to one year of age



What are the FBDR data sources?

- **Birth certificate data**
 - To construct population of interest, congenital anomaly information not used in reporting prevalence data
- Agency for Health Care Administration (AHCA) inpatient and outpatient **hospital discharge data**
- **Florida Department of Health data**
 - Regional Perinatal Intensive Care Centers (RPICC)
 - Children's Medical Services (CMS) Minimum Data Set
 - CMS Early Steps (ES)



FBDR Passive Data

- Rates and counts for selected congenital anomalies published annually in **Birth Defects Research, Part A**
- FBDR **Website** (www.fbdr.org)
 - Provides general information to the public




Florida Birth Defects Registry

Home The FBDR Birth Defects Resources Data Surveillance

County Data For Birth Defects in Florida, Florida

Florida, 1998-2005
Birth Defects for 1,659,717 1998-2005 Live Births



	Est. Cases	Frequency
Children with Structural Birth Defects	37,194	1 in 45
Specific Conditions		
Congenital Heart Defects	12,252	1 in 135
Chromosomal Abnormalities	2,555	1 in 650
Down Syndrome	2,181	1 in 761
Oral Clefts	2,258	1 in 735
Neural Tube Defects	765	1 in 2,170
Abdominal Wall Defects	1,072	1 in 1,548
Limb Malformations	489	1 in 3,394

99,999 indicates <5 case count
[Return To County Listing Page](#)

Limitations of FBDR Data

- **Only includes live births**
- Until 2006, AHCA inpatient discharge data limited to only 10 ICD-9-CM diagnosis codes and 10 procedure codes
- Single ICD-9-CM code is used to describe different malformations: (i.e. 756.79 gastroschisis/omphalocele)
- Dependent on how the condition is **noted** in the medical record, **interpreted** by the medical coder, and how it is **entered** into the hospital information system
- **No confirmation of diagnosis**
- Source data sets (AHCA and CMS) **must be** matched to a birth certificate, relies on linkage process and accuracy of data



EPHT Active Surveillance Project



Inclusion Criteria

- Presence of at least **1 of 12 structural defects** in the infant (ICD-9-CM diagnosis codes)
 - Case finding includes defect codes and maternal 655 codes (known or suspected fetal abnormality affecting the mother)
- Defect must be diagnosed **prenatally or within one year** after delivery
- **Florida residency** of mother at the time of diagnosis or delivery
- Receipt of care at one of the hospitals in the **catchment area** between January 1, 2007 and December 31, 2010



Catchment Area

Central Florida

Pinellas
Hillsborough
Polk
Orange
Seminole
Volusia
Brevard

Southwest Florida

Lee

West Florida

Escambia

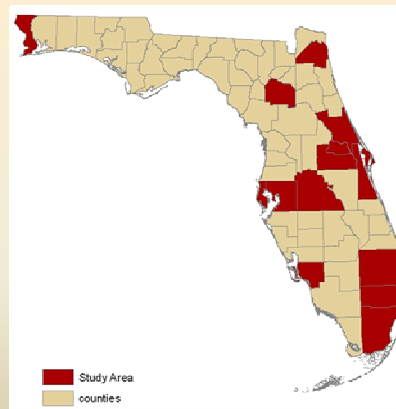
North Florida

Duval
Alachua

South Florida

Palm Beach
Broward
Miami-Dade

14 counties



Catchment Area Demographics

All Florida Resident Live Births

Catchment Area Demographics Compared to the State of Florida, 2000-2007

	EPTH Catchment Area	Florida	Captured by Catchment Area
Resident Live Births	1,268,301	1,748,203	73%
Maternal Race-Ethnicity			
NH-White	42%	48%	63%
NH-Black	24%	22%	82%
Hispanic	30%	27%	81%
Maternal Age >35 years	15%	14%	77%
Preterm birth (<37 wks)	14%	14%	74%

Data source: Florida Department of Health, office of Vital Statistics, Florida Birth Certificate, 2000-2007

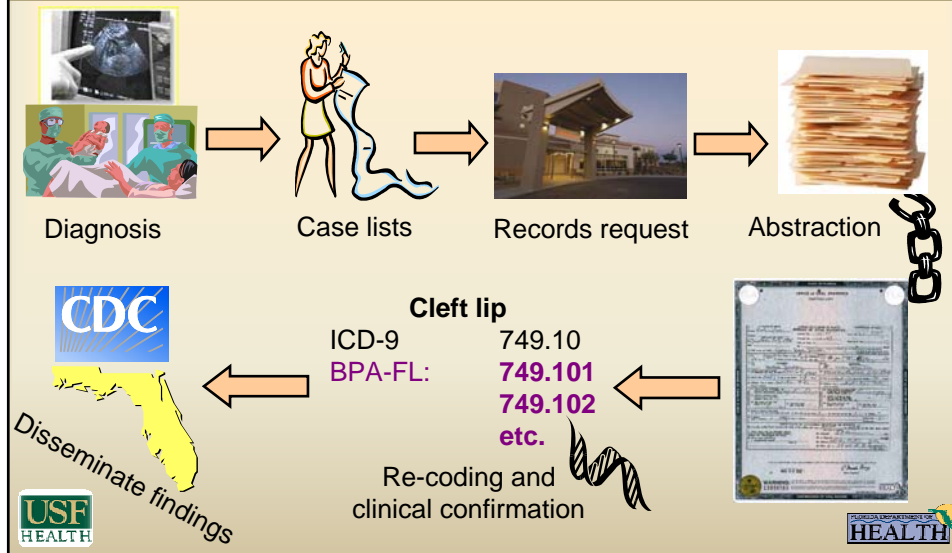


Case Ascertainment

- Hospital medical records
 - AHCA inpatient and outpatient discharge databases*
 - Maternal medical records (*includes prenatal cases*)
 - Infant medical records
- Vital Statistics data
 - Birth certificates
 - Fetal death certificates
 - Infant death certificates



Program Operation



Managing Active Surveillance

- Single abstractor for 85 catchment area hospitals
- Continual correspondence with hospitals
 - Notification of study and upcoming requests
 - Request for potential case lists
 - Request for medical record pulls
- Multiple admissions for mothers and infants
- Collection of demographic and perinatal data
- Case-classification
- **Required the development of a database management system**



Developing a database management system

- Evolved from a simple **Microsoft Access database** used in a previous active surveillance project
- Solicited recommendations from program staff, epidemiologists, and clinicians
- The principal objectives to guide the database revisions focused on:
 1. **time-saving** functionality improvements
 2. enhanced **tracking measures and reporting**
 3. real-time data validation and **quality control**



Time-saving functionality improvements

- A **menu system** was designed to ease navigation of the various project management functions
 - Access to **automated reports** were created to facilitate planning abstraction trips and to track the progress of the project
 - Direct access to a query that simplified coding congenital malformations



Record Data Management

Request Reports
Summary Reports
Appending External Data (database administrator use only)
Coding Malformations
Case Classification
Deliverables

1. Select an option above by double-clicking it or by highlighting it and clicking the next button

**USF Birth Defects Surveillance Program
Environmental Public Health Tracking Database**

ID	Mom Name	Child Name	Mom DOB	Child DOB	Abstraction Decision
05909	SAL DEL RIO, ROXANNE	SAL DEL RIO, JUAN	08/05/1980	10/10/2007	Reviewed, Abstracted
05903	PEREZ, KAREN	SALEHI, EDGAR	06/07/1975	09/01/2007	Pending Abstraction
05911	SALEMI, COZETTE	SALEMI, JASON	11/25/1970	01/02/2007	Pending Abstraction
05902	PAYNE, COZETTE	SALEMI, JAYSON	11/25/1970	01/02/2007	Reviewed, Abstracted
05908	SALEMI, JENNIFER	SALEMI, PETER	11/13/1976	12/13/2007	Pending Abstraction
05907	SALERMO, MELISSA	SALERMO, ERIC	04/07/1988	09/06/2007	Reviewed, Abstracted
05904	JOHNSON, DIANA	SALLENS, JONATHAN	06/19/1981	08/01/2007	Reviewed, Not Abstracted
05905	SMITH, LINDA	SALMON, JOSE	01/04/1966	06/15/2007	Pending Abstraction
05910	SALTERO, GABRIELLA	SALTERO, TYLER	08/19/1991	09/11/2007	Reviewed, Abstracted
05906	SALTMAN, MICHELLE	SALTMAN, MIGUEL	05/06/1971	08/20/2007	Reviewed, Not Abstracted

1. Select the field you wish to search by:

Enter all or part of the child's last name

Study ID#
Mother's Last Name
Infant's Last Name
Maternal SSN
Mother's DOB
Infants DOB

SAL

Record Not On List - Enter New Record

Main Menu Reset < Back Next >

Enhanced tracking measures and reporting

- Project management
- Automated report generation and tracking of:
 - Initial requests sent to hospitals
 - Case lists
 - Medical record requests

Enhanced tracking measures and reporting

- Entering case lists prior to entering the field
 - Each case may have multiple admissions for the mother and infant



Environmental Public Health Tracking Database

Unique STUDY ID: Date Record Created:

Case Type: Facility:

Identification Source(s): Birth Infant Death Fetal Death AHCA Inpt AHCA Outpt Hospital List

Child First: Child DOB:

Child Middle: Child SSN:

Child Last:

Mom First: Mom DOB:

Mom Middle: Mom SSN:

Mom Last:

Suspected Defect(s): Anencephaly Spina bifida HLHS Tet of Fallot Transposition Cleft Lip

Maternal Condition Cleft Palate Hypospadias Gastroschisis Upper Limb Lower Limb Down Syndrome

Other Defect (from BVS) Defect Description:

Pregnancy Outcome: Abstraction Decision:

Elective term indicated?

Reason Medical Record Not Abstracted:

Acct#	MRN#	Facility	Admit Dt	Disch Dt	Birth Adr	First Adr	On List
123456789	121121212	TAMPA GENERAL HOSPITAL	02/17/2008	02/18/2008	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
987654321	34563456	ALL CHILDRENS HOSPITAL	02/18/2008	03/01/2008	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
456678994	34563456	ALL CHILDRENS HOSPITAL	06/01/2008	06/03/2008	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
*					<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Records: 4 of 4 | No Filter | Search

Enter details regarding the first record reviewed below

Is this the birth facility: Yes
 Birth facility: TAMPA GENERAL HOSPITAL
 Type of admission: Newborn
 Transferred from:
 Discharge outcome: Transfer
 Transferred to: ALL CHILDRENS HOSPITAL
 Pediatrician name: Jim Doe Smith, DO
 Covered by medicaid: No

CLOSE Child Form Exit Form START RECORD REVIEW

Enhanced tracking measures and reporting

- Record request lists
 - Each child may appear on more than one list
 - Tracks how many times we have requested records
 - We can choose how many records we request at a time

Hospital Record Request List for TAMPA GENERAL HOSPITAL								
#	Name	DOB	SSN	MRN	Admit Dt	Dischg Dt	Mom's SSN	Study ID
Infant Records								
1	CORREIA, JANE	01/01/2007	666666666	4456465	01/01/2007	01/05/2007	555555555	05898
1	HAUSER, KIMBERLEA	01/01/2007	555555555	13132	01/01/2007	01/05/2007	555555555	05897
1	JAMES, LEBRON	01/01/2007	888888888	132123	01/01/2007	01/05/2007	555555555	05900
1	JORDAN, MICHAEL	01/01/2007	777777777	541	01/01/2007	01/05/2007	555555555	05899
1	KIRBY, RUSSELL	01/01/2007	444444444	456	01/01/2007	01/05/2007	555555555	05896
1	SALEMI, JASON	01/01/2007	222222222	4567	01/01/2007	01/05/2007	555555555	05894
1	SAMPAT, DIANA	01/01/2007	111111111	1234	01/01/2007	01/05/2007	555555555	05893
1	TANNER, JEAN PAUL	01/01/2007	333333333	8912	01/01/2007	01/05/2007	555555555	05895
1	WOODS, ELDRIDGE	01/01/2007	999999999	123	01/01/2007	01/05/2007	555555555	05901
MALF_CD	MALF	MALF_C					STUDY_ID	
749.100	cleft lip	no cleft palate; appears isolated					00033	
	cleft lip	repaired on 4th day of life; left incomplete					00174	
	cleft lip	congenital					05556	
	cleft lip	right sided					01620	
	cleft lip	isolated, left sided					04633	
	cleft lip and palate	right complete; in at 5 months for cleft lip repair					00196	
	cleft lip and palate	bilateral					04868	
	cleft lip and palate	bilateral incomplete; repaired 5/29/07					00175	
	cleft lip and palate	left unilateral complete					05053	
	cleft lip and palate	bilateral					00354	
	cleft lip and palate	large left sided hard and soft palate cleft; complete					05122	
	cleft lip and palate	cleft hard palate					04627	
	cleft lip and palate	bilateral complete; cleft lip repaired on 10/31/07					04835	
	cleft lip and palate	involving primary and secondary palate; complete					05118	

Real-time data validation and quality control

- Ensuring the collection of high quality data
 - Real time error checks
 - Malformation specifics

General Info | Admissions | ICD-9 Codes | Birth Details | Diagnostic Tests I | Diagnostic Tests II | Malformations | Malf-Specific Info | Referrals | Comments

00287

Enter child malformations

Name/description:
intestinal malrotation

Important comments/details:
floating right colon and proximal transverse colon; cecum and appendix in right upper quadrant near gallbladder

Method of diagnosis: autopsy

Timing of diagnosis: Postnatal

Malformation confirmed?

Texas 6-digit code: ██████████

[Add Another Malformation](#)

Record: 14 of 34

View existing child malformations entered

Defect	Code
absent eyelashes	
absent innominate vein	
ascites	
asd	
cleft lip and palate	
epicanthal folds	
fawn shaped pinnae	
flat nose	
flat supraorbital ridges	
hypertelorism	
hypoplastic great toenails	
hypoplastic labia majora	
interrupted aortic arch	
intestinal malrotation	
low set ears	
persistent left superior vena cava	
pleural effusions	
posteriorly rotated ears	
preauricular pits	
pulmonary hypoplasia	
redundant skin folds of the neck	
rockerbottom feet	

Record: 1 of 34

CLOSE Child Form
Exit Form
START RECORD REVIEW

Real-time data validation and quality control

- Ensuring the collection of high quality data
 - Multiple sources are utilized for case ascertainment
 - Identifying data is collected on abstracted cases as well as non abstracted cases.

Environmental Public Health Tracking Database

Unique STUDY ID: 05893 Date Record Created: 2/18/2009 2:50:58 PM

Case Type: Child Facility: TAMPA GENERAL HOSPITAL

Identification Source(s): Birth Infant Death Fetal Death AHCA Inpt AHCA Outpt Hospital List

Child First: JOHN Child DOB: 02/17/2009

Child Middle: LEE Child SSN: 123-45-6789

Child Last: DOE

Mom First: JANE Mom DOB: 06/08/1977

Mom Middle: MARY Mom SSN: 987-65-4321

Mom Last: SMITH

Suspected Defect(s): Anencephaly Spina bifida HLHS Tet of Fallot Transposition Cleft Lip

Maternal Condition Cleft Palate Hypospadias Gastroschisis Upper Limb Lower Limb Down Syndrome

Other Defect (from BVS) Defect Description: _____

Pregnancy Outcome: Live Birth Abstraction Decision: Reviewed, Abstracted

Elective term indicated?

Reason Medical Record Not Abstracted: _____

Case Classification

- Clinical geneticists recommended the addition of clinical information, methods of diagnosis, laboratory results and other diagnostic tests to the database to allow for case classification
 - Using knowledge of embryologic and pathogenetic mechanisms to create groups used for analysis more comparable
- Using the “Guidelines for Case Classification for the NBDPS” (Rasmussen, et al) as a model, we developed an **interactive flowchart** for geneticists’ use during case classification

General Info | Admissions | ICD-9 Codes | Birth Details | Diagnostic Tests I | Diagnostic Tests II | Malformations | Malf-Specific Info | Referrals | Comments **04869**

Were diagnostic tests (x-rays, ultrasound, MRIs, CTs, genetics) found in the medical record? Yes

Test Type	Test SubType	Results	Comments
Genetic	Karyotype	Normal	46, xx at 500 band resolution
Genetic	other	Normal	Test: Smith Lemli Opitz Syndrome - normal w/ reported polymorphisms; 1 seen and reported as silent mutations of no clinical signif: C189G>A;
Genetic	Microarray	Normal	myotonic dystrophy mutation analysis, no mutation analysis
Genetic	CGH	Normal	ARR CGH 1-22 (X2,X); NEGATIVE (NORMAL)
Ultrasound	Head	Abnormal	There is a single enlarged ventricle without separation. There is choroid floating within the ventricle consistent with holoprosencephaly.
Ultrasound	Head	Abnormal	Spectrum of findings most compatible with holoprosencephaly, semilobar variant
X-Ray	Chest	Normal	For tube placement
Ultrasound	Renal	Normal	Generous adrenal glands; mild left renal pelvicaliectasis

Record: 4 of 9 | No Filter | Search

CLOSE Child Form | Exit Form | START RECORD REVIEW

Unique STUDY ID: 00006 | Facility: BAYFRONT MEDICAL CENTER

Case Type: Child | Pregnancy Outcome: Live Birth

Classification: Multiple, Prev Described Pattern

Primary diagnosis:

Notes:

Documented child malformations:

- aortic regurgitation
- aortic stenosis
- asd
- d transposition of the great vessels
- intraorbital creases
- low set ears
- pda
- posteriorly rotated ears
- quadricuspid aortic valve

Record: 1 of 14 | No Filter | Search

CLASSIFY CASE | OPEN Maternal Form | OPEN Child Form | Exit Form

Case Abstraction

- The on site review of records for EPHT active surveillance began in January 2008.
- Confirmed defects abstracted

Defect	Cases	Defect	Cases
Hypospadias	239	Cleft Palate Alone	46
Trisomy 21	127	Hypoplastic Left Heart Syndrome	40
Cleft Lip with or without Cleft Palate	97	Spina Bifida without Anencephaly	32
Gastroschisis	82	Reduction deformity of the upper limbs	19
Transposition of the Great Vessels	68	Anencephaly	15
Tetralogy of Fallot	51	Reduction derformity of the lower limbs	8



Recent and Upcoming Improvements

- For time management and future planning a timer was added to the database to estimate the average time it takes to abstract a record.
- Remote case abstraction
- Improve case finding with the addition of inpatient and outpatient hospital discharge data
 - Could also be used to assess the quality of what hospitals currently submit as case lists

