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

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 exposure.
12 Different Birth Defect Indicators

Birth defects are one of the leading causes of infant deaths, and babies born with birth defects have a greater chance of being born with permanent disabilities. The cost of lifetime care for infants born 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 DEP be tracking birth defects?

Links to other websites:

- Maternal of Monday
- Florida Birth Defects Registry
- Bureau of Environmental Public Health Medicine
- Preventing Birth Defects
- Having a Healthy Pregnancy

To see indicator data, please select indicator:

Anencephaly: Number of live births with Anencephaly
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
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

<table>
<thead>
<tr>
<th>Catchment Area Demographics Compared to the State of Florida, 2000-2007</th>
</tr>
</thead>
<tbody>
<tr>
<td>EPTH Catchment Area</td>
</tr>
<tr>
<td>---------------------</td>
</tr>
<tr>
<td>Resident Live Births</td>
</tr>
<tr>
<td>Maternal Race-Ethnicity</td>
</tr>
<tr>
<td>NH-White</td>
</tr>
<tr>
<td>NH-Black</td>
</tr>
<tr>
<td>Hispanic</td>
</tr>
<tr>
<td>Maternal Age &gt;35 years</td>
</tr>
<tr>
<td>Preterm birth (&lt;37 wks)</td>
</tr>
</tbody>
</table>


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**

1. **Diagnosis**
2. **Case lists**
3. **Records request**
4. **Abstraction**

**Cleft lip**

- **ICD-9**: 749.10
- **BPA-FL**:
  - 749.101
  - 749.102
  - etc.

**Disseminate findings**

**Re-coding and clinical confirmation**

**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

USF Birth Defects Surveillance Program
Environmental Public Health Tracking Database
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
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
Real-time data validation and quality control

- Ensuring the collection of high quality data
  - Real time error checks
  - Malformation specifics
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.
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
### Diagnostic Tests

<table>
<thead>
<tr>
<th>Test Type</th>
<th>Test Subtype</th>
<th>Results</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Genetic</td>
<td>Karyotype</td>
<td>Normal</td>
<td>46, Xy at 500 band resolution</td>
</tr>
<tr>
<td>Genetic</td>
<td>other</td>
<td>Normal</td>
<td>Test: Smith Lemli Optiz Syndrome - normal k/ reported polymorphisms; 1 seen and reported as silent mutations of no clinical agnif: C1896X;</td>
</tr>
<tr>
<td>Genetic</td>
<td>Microarray</td>
<td>Normal</td>
<td>Myotonic dystrophy mutation analysis, no mutation analysis</td>
</tr>
<tr>
<td>Ultrasound</td>
<td>Head</td>
<td>Abnormal</td>
<td>There is a single enlarged ventricle without separation. There is choroid plexus within the ventricle consistent with holoprosencephaly.</td>
</tr>
<tr>
<td>Ultrasound</td>
<td>Head</td>
<td>Abnormal</td>
<td>Spectrum of findings met compatible with holoprosencephaly, semilobar variants</td>
</tr>
<tr>
<td>X-Ray</td>
<td>Chest</td>
<td>Normal</td>
<td>For tube placement</td>
</tr>
<tr>
<td>Ultrasound</td>
<td>Renal</td>
<td>Normal</td>
<td>Generous adrenal glands; mid left renal pelviectasis</td>
</tr>
</tbody>
</table>

### Classification

**Primary diagnosis:**

**Classification:**

- Multiple, freely described pattern

### Notes

- Review infant data
- Case definition met?
- Single gene condition of chromosome abnormality previously diagnosed?
- Genetic syndrome
- Exposure to known teratogen and observed defect(s) strongly associated with exposure?
- Teratogenic syndrome
- How many major defects are present?
- Are all defects of the same organ, organ system or body part?
- Are defects pathogenetically related?
- Does reviewer strongly suspect a syndrome of known etiology?
- Syndrome
- Previously described pattern present?
- Multiple - Previously described pattern
- Multiple - Pattern not previously described

### Documented Child Malformations

- Aortic regurgitation
- Aortic stenosis
- d transposition of the great vessels
- Intrauterine growth retardation
- Low set ears
- PDA
- Posteriorly rotated ears
- Cardiopulmonary valve

### Case Information

- **Unique Study ID:** 00000
- **Facility:** BAYFRONT MEDICAL CENTER
- **Case Type:** Child
- **Pregnancy Outcome:** Live Birth
- **Classification:** Multiple, freely described pattern
Case Abstraction

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

• Confirmed defects abstracted

<table>
<thead>
<tr>
<th>Defect</th>
<th>Cases</th>
<th>Defect</th>
<th>Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypospadias</td>
<td>239</td>
<td>Cleft Palate Alone</td>
<td>46</td>
</tr>
<tr>
<td>Trisomy 21</td>
<td>127</td>
<td>Hypoplastic Left Heart Syndrome</td>
<td>40</td>
</tr>
<tr>
<td>Cleft Lip with or without Cleft Palate</td>
<td>97</td>
<td>Spina Bifida without Anencephaly</td>
<td>32</td>
</tr>
<tr>
<td>Gastrochisis</td>
<td>82</td>
<td>Reduction deformity of the upper limbs</td>
<td>19</td>
</tr>
<tr>
<td>Transposition of the Great Vessels</td>
<td>68</td>
<td>Anencephaly</td>
<td>15</td>
</tr>
<tr>
<td>Tetralogy of Fallot</td>
<td>51</td>
<td>Reduction deformity of the lower limbs</td>
<td>8</td>
</tr>
</tbody>
</table>

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