Early Steps Service Coordinator Apprenticeship

Train the Trainer Workshops

The goal for these workshops is to prepare service coordinator trainers and supervisors to implement the Service Coordinator Apprenticeship Training. During the workshop you will become familiar with the training format which includes: content topics, learning strategies, and assessment requirements. You will experience a variety of learning methods, explore field activities, and role play a reflective practice session. The Apprenticeship training units are intended to complement the observation and practical experience requirements during the 90-day apprenticeship period.

Please note that this training is designed for individuals responsible for training new service coordinators. Each session will be limited to 40 participants.

10:00 am – 4:30 pm (1 hour lunch on your own)

June 9th Orlando
Lucerne Pavilion • 818 Main Lane

June 10th Tampa
Century Buick GMC / Century KIA
3308 W. Hillsborough Avenue

June 14th Chipley
Panhandle Area Educational Consortium
753 West Boulevard

June 16th Jacksonville
Jacksonville Children's Commission
1095 A. Philip Randolph Boulevard

June 21st Boynton Beach
Children's Services Council of Palm Beach County
2300 High Ridge Road

June 22nd Miami
United Way Center for Excellence in Early Education
3250 Southwest Third Avenue

Register at: **www.cpeip.fsu.edu/es**

For more information contact:

Sarah Mullane (850-922-1338) or Haylie Smith (850-245-4444 x 2267)

Baby Builders

An Exercise Program for Stronger, Healthier Babies.

PROFESSIONAL REFERENCE

Ed Gustavson, M.D., F.A.A.P.
Chief of Developmental Pediatrics
Children's Medical Center
Tulsa, Ok.

Ray Harris, M.D., F.A.A.P.
Pediatrics of Bartlesville
Bartlesville, Ok.

Keith Mather, M.D., F.A.A.P.
Pediatric Hospitalist
Cox Medical Center
Springfield, Mo.

Scott Sticksel, Psy.D
Amarillo, Tx.

Catherine Thompson PT, PhD, MS
Assistant Professor Physical Therapy Education
Rockhurst University
Kansas City, Mo.

John Treischmann, M.D. F.A.A.P.
Medical Director
Stepping Stone Developmental
and Behavioral Clinic
Hot Springs, Ar.

Terry Zuerlien, M.D.
Medical Director, Intensive Care Nursery
St. Vincent's Doctor's Hospital
Little Rock, Ar.

Baby Builders serves the Centers for Disease Control's National Center on Birth Defects & Developmental Disabilities as an external partner

57450 E. Highway 125 #615
Afton, OK 74331
www.BabyBuilders.com
918.519.8485

Baby Builders Infant Development Program

Baby Builders is being used by Early Intervention providers across the U.S. to help build health in "high-risk" children with proven exercises.

> ""This material is outstanding and shows easy to follow, step by step, instructions. This is exactly what every parent of a high-risk baby needs. It's a guide that enables parents to be proactive in working toward the goal of a healthy, happy baby."
>
> *E.E. Gustavson, M.D., F.A.A.P, Chief of Developmental Pediatrics, Children's Medical Center, Tulsa, OK*

Baby Builders (English/Spanish DVD and English book) was developed by Pediatric Physical Therapist, Jenna Zervas, MSPT.

This family-centered resource empowers families to reach their desired health outcomes in their natural environment by:

- Maximizing therapist's time by providing a visual tool to safely instruct families not seen as often as the therapist would like. (i.e. where there is a shortage of therapists)
- Empowering interventionists/other staff with tools for motor skill instruction. Baby Builder's DVD and book allows families to better understand and comply with their home exercise program.
- Providing families with proven activities that focus on treating the core problems of high risk infants: weak postural control muscles and poor coordination.
- Helping bridge cultural gaps for English speaking therapists with Hispanic families.

Baby Builders' book also includes information for preemie parents regarding the identification and respect of stress signs in regard to activities.

BABY BUILDERS PACKAGES

Baby Steps Package $1,395 50 Baby Builders DVD's (English/Spanish) and 50 Baby Builders books/book Stages (English). Unlimited additional books/book stages or DVD's at $14. (**Stages** add $225)

Baby Builders Development Package $2,395 100 Baby Builders DVD's (English/Spanish) and 100 Baby Builders books/book Stages (English). 100 Copies from printable library of Customized Baby Builders Journals and Growth Charts. Unlimited additional books/book stages or DVD's $12. (**Stages** add $430)

Baby Builders Advanced Package $5,595 250 Baby Builders DVD's (English/Spanish) and 250 Baby Builders books/book Stages (English). Unlimited printable library use of Customized Baby Builders Journals and Growth Charts. Unlimited additional books/book stages or DVD's $12. (**Stages** add $1000)

Baby Builders Training Package $9,785 500 Baby Builders DVD's (English/Spanish) and 500 Baby Builders books/book Stages (English). 1 site visit with one-half day Staff Training. Unlimited printable library use of Customized Baby Builders Journals and Growth Charts. Unlimited additional books/book stages or DVD's $11. (**Stages** add $1650)

For Custom Configuration and Greater Quantities, please contact us.

Baby Builders Book Stages: Therapists may now purchase Baby Builders book divided into its four individual stages. ($20 per book) Discounted pricing is noted above.

Baby Builders Staff Training:
$485 per hour. One half day Staff training is $1880. One full day of Staff training is $2,980. (Up to 40 participants).

NOTE: One year time frame for additional material. Prices shown are FOB source; shipping not included. Trainings do not include travel /expenses for 2.

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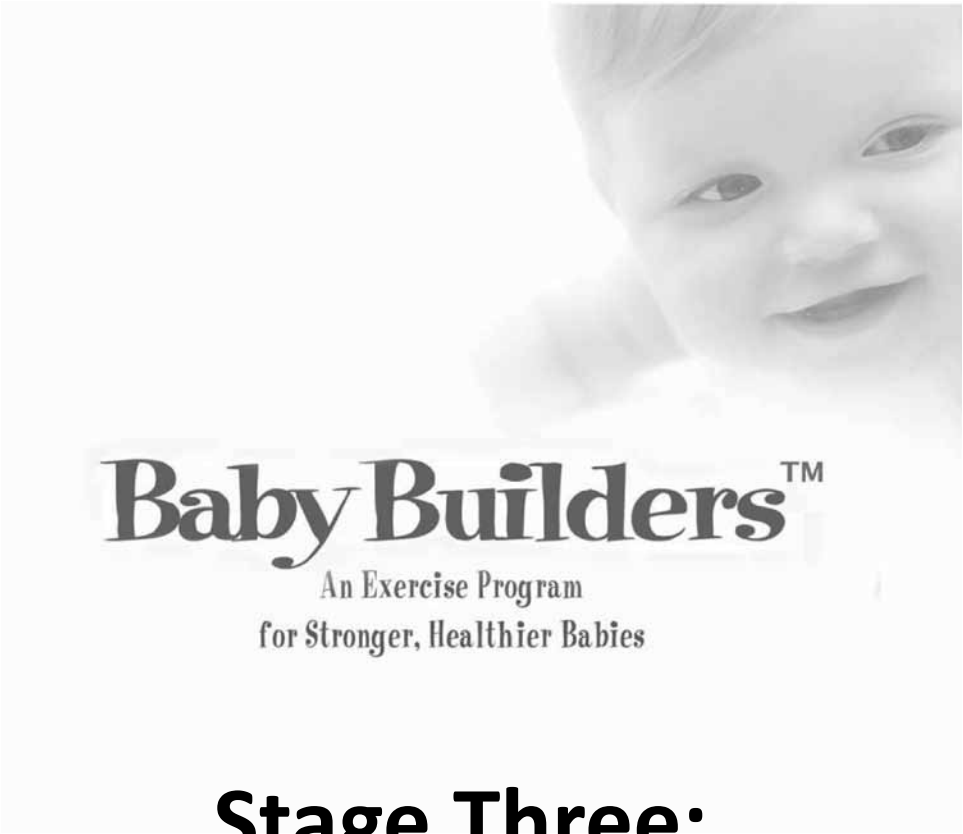

Stage Three: Movement

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Leadership Vision, L.L.C., 57450 E. Highway 125 #615, Afton, OK 74331

The information in Baby Builders is based on the research and experience of its designer, Jenna Zervas, MSPT, and is intended for informational purposes only.

The Baby Builders Exercise Program is intended to help you improve the motor skills and coordination of your infant.

The instructions and/or advice are in no way intended to be a substitute for recommendations from your health care provider. You should consult your health care provider before beginning this or any other exercise program.

The designers, producers, participants, and distributors of Baby Builders disclaim any liabilities or loss in connection with the exercise instructions and advice herein.

Baby Builders was created so you can safely and enjoyably improve your baby's strength, balance and coordination, and prevent developmental delays.

Please use the book in the following order. Only move to the next stage when your baby can easily and independently complete all the exercises in the previous stage.

1. Strength
2. Balance
3. Movement
4. Coordination

SLOWLY BEGIN THE EXERCISES WITH YOUR INFANT. Just as you need to build up your endurance and strength for a workout program, so does your infant. Gradually work up to 20-30 minutes of exercise per day over a several week period. Remember, this is hard work for your infant.

**Watch for crying and/or fussiness which may indicate that your infant needs a rest.

DEVELOPMENTAL STAGE 3: *Movement*

STAGE THREE - MOVEMENT

Sidelying to sitting	2
Hands and knees	4
Reaching on hands and knees	6
Tall kneeling	8
Pulling up to stand	10

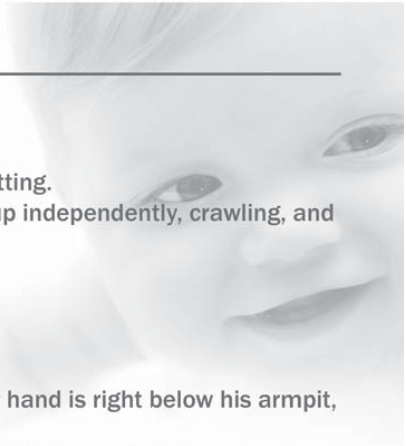
****Make sure your baby can do all the exercises in Stage 1 and Stage 2 before you begin Stage 3****

BENEFITS FOR YOUR BABY IN STAGE 3 INCLUDE:

- ★ Improved strength and balance to allow play in tall kneeling position
- ★ Ability to move from lying down to sitting up independently
- ★ Ability to push up to the hands and knees position
- ★ Improved strength and balance to allow weight shifting and reaching on hands and knees
- ★ Foundational skills for creeping on hands and knees
- ★ Ability to pull up to standing
- ★ Improved hand-eye coordination
- ★ Increased movement improves cognitive skills as baby's environment expands

NOTE: Remember to take your time with these exercises. Go slowly with your infant. Do not start this stage if your baby is under 5 months old. Your baby may not tolerate all stage 3 exercises at the same time. You may mix them up throughout the day or day to day. Try to work up to 30 minutes of exercise a day. Always watch for cues such as crying and/or fussiness that may indicate your baby needs a rest. (Do not start the "pulling up to stand" exercise until your baby can consistently do the 'tall kneeling" exercise on his own.)

Side Lying to Sitting



PURPOSE:

- Teaches baby how to move from lying down to sitting.
- Strengthens the abdominal muscles for sitting- up independently, crawling, and moving from sitting to hands and knees.

HOW TO:

- Roll baby from his stomach or back to his side.
- Put one hand on top of his upper hip.
- Slide the other hand under his chest so that your hand is right below his armpit, but is flat against his rib cage.
- Pull down gently on the hip towards the feet while lifting up slightly under the armpit.
- Continue to gently pull down on the hip and lift under his armpit, until either the baby is sitting upright or he begins to push himself up into sitting.
- Repeat this exercise on the other side.

DESIRED MOVEMENT:

- Baby should begin to push himself up into sitting after the initial pull on the hip.

UNDESIRED MOVEMENT:

Problem: Baby does not do anything, but simply lets you raise him up.

Solution: Make sure you are pulling down on the hip before you begin to lift him up.

TOY SUGGESTIONS:

Use a light-up and musical toy, placing it in front of him and close to his knees so he has to reach across his body to get it.

DAILY ROUTINE:

This is a good exercise to do when you get him out of his crib or are picking him up off the floor.

CONSULT YOUR HEALTHCARE PROVIDER IF:

►After doing this exercise for several months, baby is consistently able to do the desired movement much better on one side than the other.

►Baby is not able to move from side lying to sitting by 12 months.

Side lying to Sitting

Hands and Knees

PURPOSE:

- Teaches the baby how to stay on his hands and knees.
- Strengthens the abdominal, shoulder, and hip muscles for crawling and pulling up.
- Develops the strength and stability needed for fine motor skills and hand-eye coordination.

HOW TO:

- Place your baby on his hands and knees in front of you.
- Hold him in this position by putting one hand on his shoulder and one on his hips.
- Make sure his knees are directly under his hips and his hands are right under his shoulders.
- See if he can hold this position for several seconds while he is entertained by a toy, mirror, sibling, etc...
- As his hips get stronger, you can gradually decrease your support; first remove support him from his hips and then from his shoulder.

DESIRED MOVEMENT:

- Your baby should hold himself up on his hands and knees. Eventually, he should be able to hold this position by himself and begin to rock back and forth.

UNDESIRED MOVEMENT:

Problem 1: Baby will not bear weight on his arms.
Solution 1: Roll up a small towel and put it under baby's tummy between his shoulders and hips. This will help support some of the weight of his body, making it easier for him to push himself up with his arms.

Problem 2: Baby will not keep his knees bent once you put him in the position.
Solution 2: Put your knees up against the bottom of his feet or on either side of his knees to help hold him in this position.

DAILY ROUTINE:

This is a good activity to do when you are getting him out of his crib or up off the floor. It can also be done right after diaper changes.

Hands and Knees

CONSULT YOUR HEALTHCARE PROVIDER IF:

►Baby is not able to push up to hands and knees by 10 months.

NOTES:

Reaching on Hands and Knees

PURPOSE:

- Teaches baby how to shift his weight to one arm so he can lift the other arm up.
- Strengthens the abdominal, shoulder, and hip muscles for crawling and pulling up.
- Stimulates balance and coordination for crawling, pulling up, and walking.
- Develops the strength and stability needed for fine motor skills and hand-eye coordination.

HOW TO:

- Place your baby in the hands and knees position with a toy in front of him.
- Make sure baby's hands are under his shoulders and knees under his hips.
- Help support his non-reaching arm by placing your hand on the upper part of it.
- If necessary, put your knees up against the bottom of his feet or on either side of his knees to help hold him in this position.
- Encourage him to reach for the toy by gently lifting one of his arms toward it.
- Make sure he shifts his weight over to the arm still on the floor.

DESIRED MOVEMENT:

- Baby should balance himself on one hand and both knees, shifting his weight onto his supporting arm while he reaches with the free arm for a toy.
- Baby should reach for a toy and balance himself independently.

UNDESIRED MOVEMENTS:

Problem1: Baby attempts to reach for a toy without shifting his weight to the other arm.

Solution 1: Help him shift his weight by moving his shoulders toward the arm that will stay on the floor.

Problem 2: Baby's weight bearing arm collapses when he lifts the other arm.

Solution 2: Hold the weight bearing arm at the elbow to keep it from bending while he reaches for the toy with the other arm.

TOY SUGGESTIONS:

A toy piano or stacking rings work well. Try putting several rings out in front of him, and encourage him to put the rings in a small bucket.

Reaching on Hands and Knees

DAILY ROUTINE:

This is good physical activity to do when you are geting him out of his crib or when he is playing on the floor. It can also be done right after diaper changes. This is not a good exercise to do when your baby is tired or hungry.

CONSULT YOUR HEALTHCARE PROVIDER IF:

►Baby is not able to creep on hands and knees by 12 months.

NOTES:

Tall Kneeling

PURPOSE:

- Teaches baby how to play in the kneeling position.
- Strengthens abdominal, back, and hip muscles for crawling, pulling up, and walking.

HOW TO:

- Place your baby on his knees at a small, stable table or chair.
- Putting one hand on his chest and the other on his buttocks, gently push forward on his buttocks and backwards on his chest until he is in a tall kneeling position.
- Make sure his hips are over his knees and his shoulders are over the hips.
- Hold him there while he plays.
- As he is better able to hold this position, take away your hand that is at his chest. If he is still stable in this position, try taking away the hand at his buttocks.

DESIRED MOVEMENT:

- Baby should maintain a kneeling position while playing at a small, stable table. The hips should be over the knees and the shoulders over the hips.

UNDESIRED MOVEMENT:

Problem 1: Baby sits back on his heels instead of keeping his hips over his knees.

Solution 1: Help him move up into the tall kneeling position by gently pushing his buttocks forward so that his hips are over his knees.

DAILY ROUTINE:

This is a good activity to do during playtime on the floor. It can also be done after naps as you are getting him out of the crib. If your baby can eat small finger foods (for example, cereal), you can put the food on the table in front of him and let him have his snack while in this position.

NOTES:

Tall Kneeling

Pulling up to Stand

***NOTE:** Do not start this activity until your baby can consistently do the "Tall Kneeling" activity on his own.*

PURPOSE:

- Teaches baby how to move from a kneeling position to standing.
- Strengthens the legs, hips, and abdominal muscles for pulling up, walking, and climbing.

HOW TO:

- Place your baby on his knees at a small table or chair that will not move.
- Put your hands around his hips or waist.
- Put a toy up on top of the table just out of his reach.
- Gently pull upwards on his trunk to encourage him to stand up.
- Support him in the standing position as needed, and then repeat the exercise.

DESIRED MOVEMENT:

- Baby should stand up and reach for the toy when you pull up on his trunk.

UNDESIRED MOVEMENT:

Problem 1: Baby will not stand up.

Solution 1: Try the process again with a toy in which he is more interested.

DAILY ROUTINE:

This is a good activity to do as you get your baby out of his crib in the mornings or after naps. This activity can also be done after getting dressed or undressed.

CONSULT YOUR HEALTHCARE PROVIDER IF:

► Baby is not able to pull himself up into standing by 12 months.

NOTES:

Pulling up to Stand

What should my baby look like after completing stage 3?

- He should be able to sit by himself without support.
- He should be able to roll from tummy to back and back to tummy without help.
- He should be able to crawl on his belly.
- He should be babbling.

Baby Builders Stimulates Motor Skills Development

"Developmental psychologists have long recognized that perceptual motor development in infancy [is] the foundation of all mental life."

Jenna Zervas went to the University of Arkansas to pursue her dreams to be a pediatric surgeon and United States Olympic diver. While at Arkansas, a back injury sustained while platform diving ended Jenna's diving career, and placed her in physical therapy. This event also altered her medical ambitions. Jenna graduated cum Laude with a bachelor's degree in Zoology, with intentions of attending physical therapy school, not medical school.

In 1993 Jenna was accepted into America's leading physical therapy school, Washington University in St. Louis, and graduated with a Masters of Science degree in Physical Therapy.

Jenna soon began work as a pediatric physical therapist at St. John's Medical Center in Tulsa, Oklahoma. While at St. John's she pioneered the hospital's pediatric therapy program in their inpatient, outpatient, and pediatric and neonatal Intensive Care Units. Alongside neonatologists and developmental pediatricians, Jenna helped form a neonatal follow-up clinic for St. John's.

Together with Kimberly Beach, Jenna produced Baby Builders. Jenna has been featured on television, radio, and newspaper. She currently resides with her husband Chris in Oklahoma. They have four young children.

ENDNOTES

Lockman, JJ, Thelen E. "Developmental Bodynamics: Brain, Body, Behavior Connections." Child Development. 1993. 64, 953-959.

The Baby Builder's Training Course

Baby Builders Training

Baby Builders offers training to organizations involved in child development. The program has proven to be a great investment as participants discover new truths in infant health.

Who should attend Baby Builders' training?

P.T.'s, O.T.'s, Speech Therapists, Child life specialist, and early interventionists working in the area of infant development. Organizations implementing Baby Builders into their care for families would also greatly benefit from the training. Participants have received continuing education credit.

What does the training entail:

Trainings are tailored to fit the needs of your organization! Typically our program is designed to empower participants in their care for infants who may be at risk for developmental delays.

We have provided trainings that: feature literature updates in the area of infant development and care; teach participants how to recognize abnormal development; provide instruction in gross and fine motor skill stimulation for infants with developmental delays; and much more.

Most presentations include hands on work with infants (or dolls) and training on the implementation of Baby Builders' infant exercise program.

How long does the training last?

Our trainings are designed to fit your company's needs. The length of training depends on the size of the group and the group's needs.

Why would my company need your training?

Baby Builders is helping organizations working with infants educate their staff to best serve families with children at risk. With tightening budgets therapists often are needed to work outside their area of specialty; we provide helpful insights and instruction into motor skill development and stimulation.

Baby Builders training helps therapists and the other specialists recognize needs, serve families and, when appropriate implement Baby Builders book and DVD into family's care.

What is the cost of training for us?

Trainings are tailored to meet specific audience needs. Pricing is based on preparation, time, audience size and travel. Please contact us for specific training pricing and details.

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The Baby Builder's Training Course
Objectives

1. Attendees will have a good understanding of the current research conclusions pertaining to infants at risk for developmental delays.

2. Attendees will be able to quickly identify infants at risk for delayed development.

3. Attendees will improve their ability to evaluate the medical history of infants at risk for delayed development.

4. Attendees will be able to assess/recognize an infant with hypotonia, asymmetry, hypertonia, delayed motor skills, and poor postural control.

5. Attendee will have a good understanding of what postural control is and how to identify a weakness in the postural control musculature.

6. Attendee will be able to apply techniques to improve postural control with an infant from birth to walking.

7. Attendees will be able to teach the Baby Builder's exercise program to parents in the home environment.

8. Attendees will have a good understanding of how to incorporate Baby Builders into the activities of daily living.

Baby Builders

An Exercise Program for Stronger, Healthier Babies.

Birth Defects Profile

Florida

1 in 28 infants are born with a major birth defect in Florida.

Birth defects are the leading cause of infant deaths in Florida.

In the U.S., $2.6 billion are spent annually on hospitalization cost for birth defects.

In 2007, more than 9,000 infants were born with a major birth defect in Florida.

The Florida Birth Defects Registry (FBDR):

▶Provides timely and accurate public health information on birth defects that may be used to monitor rates, investigate causes, develop prevention strategies, detect clusters, and make policy decisions

▶Addresses and responds to community concerns about environmental effects on birth defects and birth outcomes

▶Develops strategies for implementing and evaluating prevention efforts

▶Provides data to study the causes of birth defects and epidemiologic studies to inform prevention efforts

In 2009, Florida was home to over 3.5 million women of reproductive age, including:

▶**1.8 million** White non-Hispanic women

▶**780,000** Black non-Hispanic women

▶**875,000** Hispanic women

Every year in Florida:

▶About **230,000** babies are born

▶**9,000** infants with a major structural and/or genetic birth defect are identified.

Frequency and prevalence rates of selected birth defects for Florida and the U.S., The Florida Birth Defects Registry 1998–2007.

BIRTH DEFECT	FLORIDA		UNITED STATES[1]	
	Average annual no. of cases	Birth prevalence[2]	Average annual no. of cases	Birth prevalence[2]
CENTRAL NERVOUS SYSTEM				
Anencephalus	10	0.5	1,009	2.5
Spina bifida without anencephalus	70	3.3	1,477	3.7
CARDIOVASCULAR				
Transposition of great arteries	94	4.4	1,901	4.7
Tetralogy of Fallot	114	5.3	1,574	3.9
Coarctation of the aorta	125	5.9	n/a	n/a
Hypoplastic left heart syndrome	59	2.8	975	2.4
OROFACIAL				
Cleft lip with & without cleft palate	181	8.5	4,209	10.5
Cleft palate without cleft lip	110	5.1	2,567	6.4
MUSCULOSKELETAL				
Upper limb defect	40	1.9	1,521	3.8
Lower limb defect	29	1.4	763	1.9
Gastroschisis	75	3.5	1,497	3.7
CHROMOSOMAL				
Down syndrome	280	13.1	5,132	12.8
AVERAGE NO. OF LIVE BIRTHS	231,508		4,040,000	

[1]Pooled Data from 1999–2001 [2]Rates are calculated per 10,000 live births

march of dimes

Funded by a community grant from the March of Dimes. This material is for information purposes only and does not constitute medical advice. Opinions expressed in this material are those of the author and do not necessarily reflect the views of the March of Dimes.

FLORIDA DEPARTMENT OF HEALTH

JANUARY 2011

Birth Defects Profile

Florida

Economic impact of birth defects for Florida:

▶Each case of spina bifida is estimated to cost **$636,000** in lifetime societal costs. Each year, 70 cases of spina bifida are identified in Florida with an estimated cost of **$44.5 million**.

▶Approximately 280 children are born with Down syndrome in Florida each year, corresponding to **$126 million** in total lifetime medical, non-medical, and indirect costs.

▶The mean cost of hospitalizations for a child with an orofacial cleft, within the first two years of life, is **$21,090**. Every year, 290 babies are born with an orofacial cleft in Florida.

▶Gastroschisis repair costs (in 1992) was estimated at **$108,000**; approximately 75 cases are identified each year in Florida corresponding to **$8.1 million**.

Of the 230,000 babies born EACH YEAR in Florida approximately:[1]

▶**100,000 or 43%** of births are covered by Medicaid.

▶**92,500 or 40%** are born to an overweight or obese mother. Overweight and obese women may be more likely to have a baby born with a congenital heart defect, neural tube defect, or limb defects, compared to women with normal pre-pregnancy weight.

▶**66,000 or 29%** are born to a mother of Hispanic ethnicity. Hispanic ethnicity is a risk factor for neural tube defects such as spina bifida.

▶**48,000 or 21%** are born to a Black mother. Infants born to black women have higher rates of infant mortality, low birth weight, and specific congenital heart defects, such as tetralogy of Fallot.

▶**37,700 or 16%** of them are born to women over 18 years of age without a high school education. Lack of education is associated with an increased risk for low-birth weight babies.

▶**33,000 or 14%** are born to women 35 years or older. Women over the age of 35 have a higher risk of chromosomal birth defects, such as Down syndrome, and may be more likely to have pregnancy complications.

▶**25,500 or 11%** are born pre-term or less than 37 weeks gestation. These babies are 3 times more likely to die in their first year of life, and are at an increased risk for breathing and feeding problems, as well as long lasting disabilities.

▶**25,000 or 11%** are born to teenage mothers between the ages of 15 and 19. Among women of young maternal age there is a 10 times increased risk for an abdominal wall defect, called gastroschisis.

▶**20,000 or 9%** weigh less than 2500 grams or 5½ lbs. Low birth weight babies are at increased risk for serious health problems, including respiratory and intestinal disorders, and bleeding in the brain.

▶**21,000 or 9%** of births are to mothers who report smoking during their pregnancy. Cigarette smoking is a risk factor for oral facial clefts, preterm birth, and low birth weight.

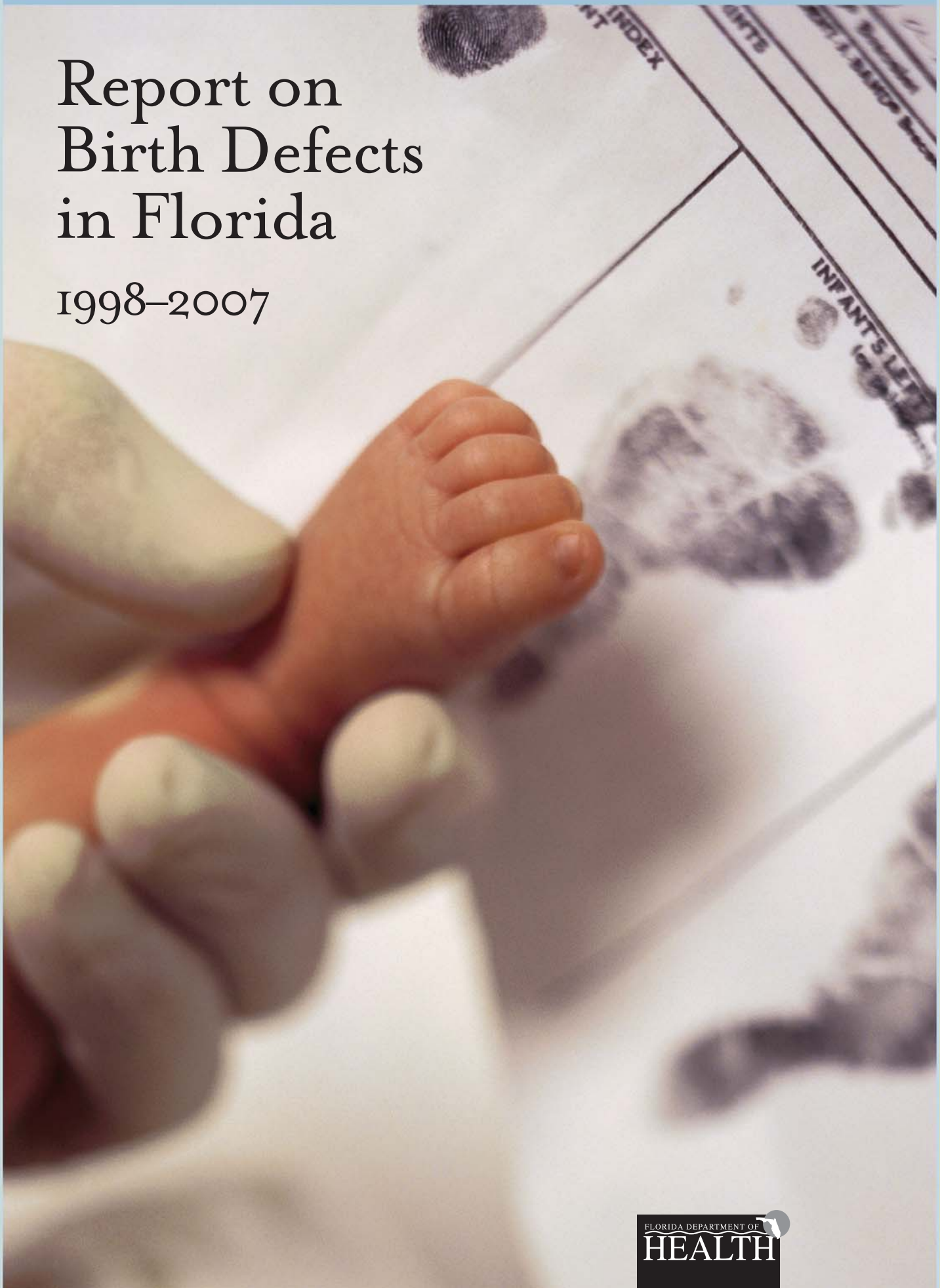
▶**9,100 or 4%** of births are to mothers with gestational or pre-gestational diabetes.[2] Research shows maternal diabetes as a risk factor for congenital heart and neural tube defects.

The causes of 65% of birth defects are unknown and many occur early in pregnancy before a woman knows she is pregnant. Women can take action to help prevent birth defects by planning their pregnancy and seeing their health care provider prior to becoming pregnant to discuss family history, use of medications, or chronic health conditions such as obesity, diabetes or epilepsy. Fetal Alcohol Syndrome is 100% preventable if a woman does not drink alcohol while she is pregnant. Women should take a multi-vitamin with 400 mcg of folic acid before and during pregnancy to prevent serious birth defects of the brain and spine called neural tube defects. It is also important that women who are pregnant or planning to become pregnant eat a well-balanced diet, exercise moderately, and avoid tobacco, illicit drugs, and chemicals that may cause harm.

Data Sources:
1. Florida CHARTS (www.floridaCHARTS.com).
2. The Florida Birth Defect Registry pooled CY March 2004–December 2007 (www.fbdr.org).

Report on Birth Defects in Florida

1998–2007



FLORIDA DEPARTMENT OF HEALTH

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Additional Information and publications can be found on the internet at: www.fbdr.org.

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Message from the Director

January 25, 2011

To Whom It May Concern:

It is our pleasure to provide this Report on Birth Defects in Florida, 1998–2007 prepared by the Florida Department of Health, Division of Environmental Health, Bureau of Environmental Public Health Medicine.

This report provides data on the occurrence of birth defects in Florida. We have included information about how the department collects, analyzes and disseminates information about birth defects. The Florida Birth Defects Registry (FBDR) is a statewide population-based passive surveillance program that identifies birth defects in infants through age one born to Florida residents.

Birth defects are one of the leading causes of infant mortality in Florida, causing one in five infant deaths. Effects of birth defects can range from mild to severe and can result in debilitating illness, long-term disability or death. A strong surveillance program is critical to monitoring trends over time, identifying risk factors, contributing data for research into causes, developing and evaluating prevention programs and responding to the needs and concerns of families and communities.

We hope that this report is useful to policy leaders, health care providers, child health advocates, educators, researchers and most importantly families. We thank you for your interest in this critical public health issue. By working together we can move closer to ensuring the health of all babies born in Florida.

Sincerely,

Lisa Conti, DVM, MPH, DIPL. ACVPM, CEHP
Director, Division of Environmental Health

Executive Summary

1 in 28 infants are born with a major birth defect in Florida.

Birth defects are the leading cause of infant deaths in Florida.

In the U.S., $2.6 billion are spent annually on hospitalization cost for birth defects.

In 2007, more than 9,000 infants were born with a major birth defect in Florida.

In the United States, one out of every 33 babies is born with a major birth defect.[1] Birth defects are the leading cause of infant death, contribute to life-long disability and developmental problems and account for 30% of pediatric hospital admissions.[1,2,3] The need for birth defect surveillance, education, and intervention activities in the state of Florida is illustrated by the diverse geography and demography, as well as the large proportion of live births that occur to women at high risk for birth defects. Three and a half million women of reproductive age (15–44 years) reside in Florida having approximately 230,000 annual live births; 26% of live births occur to women under 20 or over 35 years of age, and more than 50% of live births are to women of Hispanic or African American race/ethnicity.[6]

The Florida Birth Defects Registry (FBDR) is a passive statewide population-based surveillance system. The FBDR utilizes and links multiple datasets, including vital statistics and hospital records, to identify any infant born after January 1, 1998 with a structural, genetic, or other specified birth outcome that can adversely affect the infant's health or development diagnosed within the first year of life. From 1998 through 2007, the FBDR has identified approximately 70,000 infants born with a major birth defect in Florida, and includes demographic and clinical information for 2,135,000 live births.

The annual prevalence rate for all birth defects in Florida, reported to the Center for Disease Control and Prevention (CDC) and the National Birth Defects Prevention Network (NBDPN) (Appendix 3), is 320 cases per 10,000 live births. However, examining specific congenital anomalies provides more information about how different types of birth defects affect the residents of Florida.

Neural Tube Defects Rates of neural tube defects (NTDs) have decreased 18% from 1998 to 2007. National and state campaigns to increase folic acid consumption among women of reproductive age have played a large role in reducing the annual number of spina bifida cases from 92 in 1999 to 57 in 2006. This decrease translates into direct and indirect costs savings of more than $22 million.[9,10,12] Hispanic ethnicity is a risk factor for neural tube defects, such as spina bifida.[1,11] Hispanic residents in Florida have a diverse ethnic background including: Mexican, Puerto Rican, Cuban, as well as Central and South American ethnicities. FBDR data shows that Puerto Rican and Mexican sub-groups have the highest risk for NTDs, while Cubans have much lower rate of NTDs compared to white non-Hispanics.

Down Syndrome The prevalence of Down syndrome has not changed significantly from 1998 through 2007 and is consistent with national prevalence rate estimates of 13 per 10,000 live births. Each year in Florida, 280 infants are born with Down syndrome, corresponding to $126 million in lifetime medical, non-medical, and indirect costs.[15] Advanced maternal age is a risk factor for Down syndrome-affected pregnancy.[1] Using FBDR data a 10-fold increase in risk was identified for women over the age of 40 years.

Executive Summary

Birth defects are abnormal conditions that occur before birth. Some are mild—like an extra finger or toe. Some are very serious—like a heart defect. They can cause physical, mental or medical problems. Some like Down syndrome are caused by genetic factors. Others are caused by certain drugs, medicines or chemicals.

Congenital Heart Defects Congenital heart defects comprise the largest group of congenital anomalies and are the leading cause of birth defect-related deaths. Coarctation of the aorta has a prevalence rate of 5.8 per 10,000 live births. The prevalence rate of tetralogy of Fallot (TOF) is higher than the national estimate, at 5.3 compared to 3.9 per 10,000 live births. Florida rates of transposition of the great arteries, at 4.4 per 10,000 live births, and hypoplastic left heart syndrome, at 2.8 per 10,000 live births, are similar to national rates.

Cleft Lip Prevalence rates of cleft lip with and without cleft palate and cleft palate without cleft lip, in Florida, are lower than national rates. Additionally, annual rates of cleft lip with and without cleft palate in Florida has a statistically significant decreasing trend of 1.7% per year (p-trend=0.006). Maternal smoking and obesity are risk factors for orofacial clefts.[1,23,24]

Gastroschisis An increased prevalence rate of gastroschisis in Florida is associated with young maternal age. FBDR data shows that women under 20 years of age experience a 10-fold increase in risk compared to women over 25 (PR=10.8, p-value<0.0001).

Fetal Alcohol Spectrum Disorders The prevalence of fetal alcohol spectrum disorders (FASDs) in Florida is unavailable due to a multitude of methodological difficulties in case identification and ascertainment. FASDs are the leading cause of preventable mental retardation.[36,37] Nationally, FASDs are estimated to occur at a rate of 1 per 100 live births.[40] FASDs are 100% preventable if a woman abstains from alcohol during pregnancy.

Congenital Abnormalities The causes of 65% of congenital abnormalities are unknown.[4,43] In general, birth defects are hypothesized to be caused by a complex interaction between genetics and the environment. Research in this field is complicated by difficulty obtaining accurate measures of exposure, variability associated with organogenesis and embryologic development, and low statistical power due to low numbers of specific congenital anomalies.[46]

The FBDR constitutes a statewide, population-based, cost-effective registry to identify infants born with birth defects within a large, multiethnic population.

The accuracy, completeness, and timeliness of FBDR data are affected by the limited case definition and the passive surveillance nature of the registry. The FBDR excludes birth defect diagnoses among stillbirths and terminations of pregnancy. This may result in underestimated prevalences, particularly for defects with high mortality (e.g. anencephaly). Additionally, only birth defect cases diagnosed within the infant's first year of life are included in the FBDR, which may contribute to underestimation of prevalence for defects that are identified later in life (e.g. certain congenital heart defects, FASD). Also, the linkage algorithms employed to develop the registry rely heavily upon the mother and/or infant having a valid social security number (SSN). This has the potential to result in a disproportionately higher degree of under ascertainment among subsets of the population that are more likely to have inaccurate or missing SSNs (e.g. immigrants, minorities). The FBDR lacks the ability to confirm birth defect cases through medical record review and abstraction, possibly resulting in misclassified, non-specific, and false positive diagnoses. Finally, the registry is reliant upon the acquisition, preparation, and linkage of source datasets presently lagging two years behind.

Despite these limitations, the FBDR constitutes a statewide, population-based, cost-effective registry to identify infants born with birth defects within a large, multiethnic population. Florida contributes substantially to various national collaborative projects with the NBDPN. The FBDR data helps health policy leaders and child health advocates anticipate resource needs and secure funding for services. The data also helps guide public health professionals in targeting areas and populations in which primary prevention activities would make the largest difference in the lives of infants and families.

The Department of Health is the only agency in Florida with authority to create confidential disease registries in accordance with s. 381.0031, F.S. Although information on birth defects can be found in multiple data sets, the FBDR is the only data source where data are combined with other demographic, clinical and maternal and child health information for analysis and reporting on the occurrence of birth defects in Florida. Data on trends, risk factors, costs, access to services, and effectiveness of prevention programs are analyzed and interpreted at the county and state level for use by health policy leaders, county health departments, Healthy Start Coalitions, child health advocates, health care providers and researchers.

Florida's Birth Defect Profile

The Florida Birth Defects Registry (FBDR):

▶Provides timely and accurate public health information on birth defects that may be used to monitor rates, investigate causes, develop prevention strategies, detect clusters, and make policy decisions

▶Addresses and responds to community concerns about environmental effects on birth defects and birth outcomes

▶Develops strategies for implementing and evaluating prevention efforts

▶Provides data to study the causes of birth defects and epidemiologic studies to inform prevention efforts

In 2009, Florida was home to over 3.5 million women of reproductive age, including:

▶**1.8 million** White non-Hispanic women

▶**780,000** Black non-Hispanic women

▶**875,000** Hispanic women

Every year in Florida:

▶About **230,000** babies are born

▶**9,000** infants with a major structural and/or genetic birth defect are identified.

Economic impact of birth defects for Florida:

▶Each case of spina bifida is estimated to cost **$636,000** in lifetime societal costs. Each year, 70 cases of spina bifida are identified in Florida with an estimated cost of **$44.5 million**.

▶Approximately 280 children are born with Down syndrome in Florida each year, corresponding to **$126 million** in total lifetime medical, non-medical, and indirect costs.

▶The mean cost of hospitalizations for a child with an orofacial cleft, within the first two years of life, is **$21,090**. Every year, 290 babies are born with an orofacial cleft in Florida.

▶Gastroschisis repair costs (in 1992) was estimated at **$108,000**; approximately 75 cases are identified each year in Florida corresponding to **$8.1 million**.

Frequency and prevalence rates of selected birth defects for Florida and the U.S., ▼The Florida Birth Defects Registry 1998–2007.

BIRTH DEFECT	FLORIDA		UNITED STATES[1]	
	Average annual no. of cases	Birth prevalence[2]	Average annual no. of cases	Birth prevalence[2]
CENTRAL NERVOUS SYSTEM				
Anencephalus	10	0.5	1,009	2.5
Spina bifida without anencephalus	70	3.3	1,477	3.7
CARDIOVASCULAR				
Transposition of great arteries	94	4.4	1,901	4.7
Tetralogy of Fallot	114	5.3	1,574	3.9
Coarctation of the aorta	125	5.9	n/a	n/a
Hypoplastic left heart syndrome	59	2.8	975	2.4
OROFACIAL				
Cleft lip with & without cleft palate	181	8.5	4,209	10.5
Cleft palate without cleft lip	110	5.1	2,567	6.4
MUSCULOSKELETAL				
Upper limb defect	40	1.9	1,521	3.8
Lower limb defect	29	1.4	763	1.9
Gastroschisis	75	3.5	1,497	3.7
CHROMOSOMAL				
Down syndrome	280	13.1	5,132	12.8
AVERAGE NO. OF LIVE BIRTHS	**231,508**		**4,040,000**	

1. Pooled Data from 1999–2001
2. Rates are calculated per 10,000 live births

Florida's Birth Defect Profile

Of the 230,000 babies born EACH YEAR in Florida approximately:[1]

▶**100,000 or 43%** of births are covered by Medicaid.

▶**92,500 or 40%** are born to an overweight or obese mother. Overweight and obese women may be more likely to have a baby born with a congenital heart defect, neural tube defect, or limb defects, compared to women with normal pre-pregnancy weight.

▶**66,000 or 29%** are born to a mother of Hispanic ethnicity. Hispanic ethnicity is a risk factor for neural tube defects such as spina bifida.

▶**48,000 or 21%** are born to a Black mother. Infants born to black women have higher rates of infant mortality, low birth weight, and specific congenital heart defects, such as tetralogy of Fallot.

▶**37,700 or 16%** of them are born to women over 18 years of age without a high school education. Lack of education is associated with an increased risk for low-birth weight babies.

▶**33,000 or 14%** are born to women over the age of 35. Women 35 years or older have a higher risk of chromosomal birth defects, such as Down syndrome, and may be more likely to have pregnancy complications.

▶**25,500 or 11%** are born pre-term or less than 37 weeks gestation. These babies are 3 times more likely to die in their first year of life, and are at an increased risk for breathing and feeding problems, as well as long lasting disabilities.

▶**25,000 or 11%** are born to teenage mothers between the ages of 15 and 19. Among women of young maternal age there is a 10 times increased risk for an abdominal wall defect, called gastroschisis.

▶**20,000 or 9%** weigh less than 2500 grams or 5½ lbs. Low birth weight babies are at increased risk for serious health problems, including respiratory and intestinal disorders, and bleeding in the brain.

▶**21,000 or 9%** of births are to mothers who report smoking during their pregnancy. Cigarette smoking is a risk factor for oral facial clefts, preterm birth, and low birth weight.

▶**9,100 or 4%** of births are to mothers with gestational or pre-gestational diabetes.[2] Research shows maternal diabetes as a risk factor for congenital heart and neural tube defects.

Data Sources:
1. Florida CHARTS (www.floridaCHARTS.com).
2. The Florida Birth Defect Registry pooled CY March 2004–December 2007 (www.fbdr.org).

The causes of 65% of birth defects are unknown and many occur early in pregnancy before a woman knows she is pregnant. Women can take action to help prevent birth defects by planning their pregnancy and seeing their health care provider prior to becoming pregnant to discuss family history, use of medications, or chronic health conditions such as obesity, diabetes or epilepsy. Fetal Alcohol Syndrome is 100% preventable if a woman does not drink alcohol while she is pregnant. Women should take a multi-vitamin with 400 mcg of folic acid before and during pregnancy to prevent serious birth defects of the brain and spine called neural tube defects. It is also important that women who are pregnant or planning to become pregnant eat a well-balanced diet, exercise moderately, and avoid tobacco, illicit drugs, and chemicals that may cause harm.

Background

In the United States, one out of every 33 babies is born with a major birth defect.[1] Birth defects are the leading cause of infant mortality, the 5th leading cause of years of potential life lost, contribute to life-long disability and developmental problems and account for 30% of pediatric hospital admissions.[1, 2, 3] Despite their substantial impact, only 35% of birth defects have a known cause and research suggests a complex interaction between genetic and environmental factors.[4] Surveillance activities are important for tracking the occurrence of birth defects and identifying trends, developing and evaluating prevention programs, assisting families with referral for services, identifying potential risk factors and shaping etiological hypotheses for follow-up research.

The Florida Birth Defects Registry

In 1997, the Florida Department of Health received funding to operate and manage a statewide birth defects registry in response to the public's ongoing concern about birth defects and environmental hazards.

State Characteristics: The Past 10 Years

With 19 million people in 2007, Florida is the 4th most populous state and ranks 4th in live births in the nation.[5] Between 1998 and 2007, the annual number of live births increased from 195,000 to 239,000. Approximately 3.5 million women of reproductive age (15–44 years) reside in Florida.[6] Twelve percent of live births in the state occur to women under 20 years of age, and another 14% to women over 35 years old. Live births to minority populations currently account for more than 50%, or 1.1 million live births in Florida from 1998–2007, and half of these live births are to women of Hispanic ethnicity. National vital statistics from 2007 reported Florida having 51,800 live births to African American women, the highest frequency nationwide.[5] The demographic characteristics of Florida's women of reproductive age, specifically the proportion of high-risk groups, underscore the need for birth defects surveillance, education, and intervention activities in the state.

Surveillance Authority

In 1997, the Florida Department of Health (FDOH) received funding to operate and manage a statewide birth defects registry in response to the public's ongoing concern about birth defects and environmental hazards. On July 4th 1999, congenital malformations were added to the list of reportable diseases/conditions in Florida (Florida Statues 381.0031; Rule 64D-3.035, Florida Administrative Code), establishing the legal authority to conduct birth defects surveillance. The mission of the Florida Birth Defects Registry (FBDR) is to protect and promote the health of everyone in Florida by detecting, investigating, and preventing birth defects. Specific functions include 1) identify patterns of birth defects; 2) identify risk factors; 3) investigate and research causes of birth defects; 4) help prevent birth defects; 5) study long-term outcomes; and 6) promote teamwork and partnerships.

Surveillance Methodology

Florida is a large, diverse state, geographically and demographically. This presents challenges for implementing a registry capable of ascertaining all birth defects. The ideal surveillance program relies on an active case ascertainment methodology. This is a labor and resource intensive strategy, which necessitates an adequate workforce in order to identify potential cases through site visits to facilities around the state, and confirm each birth defect diagnosis through medical record review. Although a registry relying on active case finding would result in the most complete, timely and accurate surveillance data, the associated costs are prohibitively high. An alternative, more cost-effective approach is a passive system, in which a program receives their information on infants with birth defects from existing data sources. In Florida, we operationalize this approach by linking secondary, administrative data sources together and review the resultant records for specific International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) diagnosis codes indicative of a birth defect. In

From 1998 through 2007, the FBDR has identified approximately 70,000 infants born with a major birth defect in Florida and includes demographic and clinical information for 2,135,000 live births.

contrast to an active surveillance approach, this strategy carries limitations and a diminished overall data quality. However, it keeps costs low enough to allow for statewide coverage. Thus, understanding its current fiscal constraints, the FBDR utilizes the aforementioned population-based, statewide passive surveillance system to establish an unduplicated inventory of infants with birth defects in Florida.

To construct the FBDR, a primarily deterministic linking methodology is used to match an infant from his or her birth record to administrative data sources, including Agency for Health Care Administration (AHCA) hospital discharge and ambulatory/outpatient databases, Regional Perinatal Intensive Care Centers (RPICC) data, Children's Medical Services (CMS) case management and Early Steps program data. The key variables used for linking are social security number, the infant's birth date, sex, hospital of birth, and zip code. The methodology includes a series of iterations, for exact and partial matches of these variables, as well as limited manual review. The population of interest, which is established by the birth record from Vital Statistics, includes all live births to Florida resident mothers occurring on or after January 1, 1998. The criteria for inclusion into the birth defect registry as a case are based upon identification of one or more structural, genetic, or other specified birth outcomes that can adversely affect an infant's health and development, and is diagnosed within the first year of life. From 1998 through 2007, the FBDR has identified approximately 70,000 infants born with a major birth defect in Florida and includes demographic and clinical information for 2,135,000 live births.

To establish, operate, and maintain the FBDR, the FDOH has worked collaboratively with several state universities on activities including medical consultation, data linking, management and analysis, education and prevention programs, and research. University staff contribute strong clinical, epidemiological, and research capabilities and represent Florida's multi-disciplinary approach to birth defects surveillance. The FBDR hosts a website (www.fbdr.org) that provides defect frequencies and rates, links to relevant resources, and information for the general public and health care providers.

Selected Birth Defects

Table 1 presents the number of cases and birth prevalence of selected birth defects of public health significance, demonstrating their impact in Florida. The remainder of this report will focus on the defects in this table with more detail.

Table 1. Frequency and prevalence of selected birth defects in Florida, 1998–2007

BIRTH DEFECT	CASES[1]	RATE[2]	95% CI[3]	FREQUENCY[4]
Anencephaly	97	0.45	(0.37, 0.55)	1 in 22,026
Spina bifida w/o anencephaly	699	3.27	(3.04, 3.53)	1 in 3049
Trisomy 21 (Down syndrome)	2800	13.11	(12.64, 13.61)	1 in 763
Coarctation of the aorta	1253	5.87	(5.55, 6.20)	1 in 1704
Tetralogy of Fallot	1137	5.33	(5.02, 5.64)	1 in 1876
Transposition of the great arteries	937	4.39	(4.12, 4.68)	1 in 2278
Hypoplastic left heart syndrome	587	2.75	(2.54, 2.98)	1 in 3636
Cleft lip w/ and w/o cleft palate	1814	8.50	(8.11, 8.90)	1 in 1176
Cleft palate w/o cleft lip	1095	5.13	(4.83, 5.44)	1 in 1949
Reduction deformity: lower limbs	288	1.35	(1.20, 1.51)	1 in 7404
Reduction deformity: upper limbs	402	1.88	(1.71, 2.08)	1 in 5319
Gastroschisis	750	3.51	(3.27, 3.77)	1 in 2849
Pyloric stenosis	5397	25.28	(24.61, 25.96)	1 in 396
Trisomy 13	228	1.07	(0.94, 1.22)	1 in 9346
Trisomy 18	340	1.59	(1.43, 1.77)	1 in 6250

1. Case counts include only live births; fetal deaths, stillbirths and other terminations are excluded
2. Rate per 10,000 Florida resident live births
3. 95% Confidence intervals (CI) calculated as [Rate/EXP (1.96*sqrt(1/cases), Rate * EXP (1.96*sqrt(1/cases)]
4. Estimated frequency of occurrence in a given number of Florida resident live births

Selected Birth Defects

Neural Tube Defects

A neural tube defect (NTD) is a birth defect in which the structure that forms the brain and spinal cord (i.e., neural tube) fails to develop properly during the first four weeks of pregnancy.[1] Two of the most commonly occurring NTDs are anencephaly and spina bifida. National annual rates for the prevalence of these conditions are 2.50 and 3.68 per 10,000 live births, respectively.[7] These national estimates are based on data from active surveillance systems in 11 states.

Figure 1. Live birth prevalence rates of neural tube defects in Florida, by birth year and defect type, 1998–2007

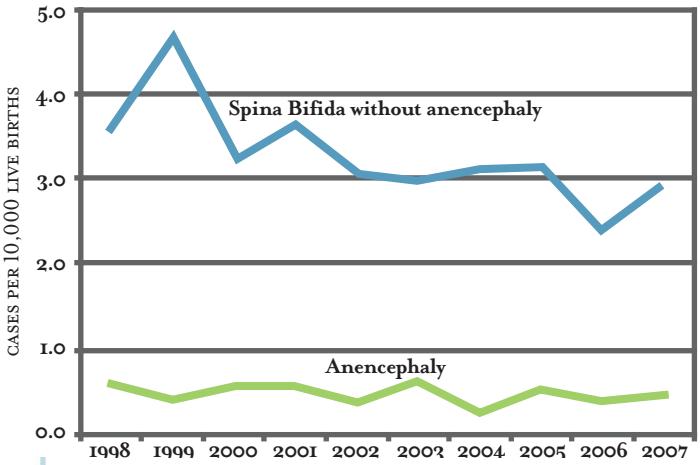
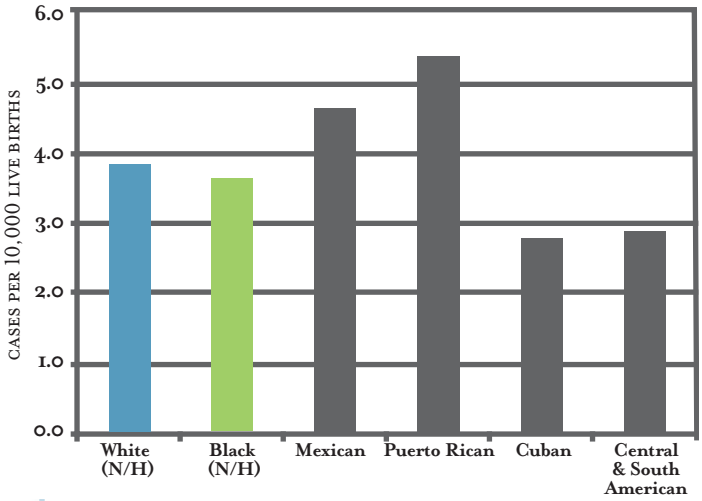


Figure 2. Live birth prevalence rates of spina bifida and anencephaly in Florida, by maternal race and Hispanic ethnicity, 1998–2007



Anencephaly occurs when the cranial portion of the neural tube fails to close, resulting in incomplete development of the brain. Infants with anencephaly are unable to survive outside of the womb.[1] When carried to term, they are either stillborn or die shortly after birth. In Florida, annual prevalence of anencephaly (0.45 per 10,000 live births) has been consistently lower than the national rate (2.50 per 10,000 live births). This is due, in part, to the fact that national rates also allow for inclusion of spontaneous and elective terminations, whereas Florida only considers live-born cases in rate calculations. Our underestimation may also be attributed to the FBDR's passive case-finding approach. Lethal defects such as anencephaly may result in an infant dying before a hospital discharge record is generated. Since the FBDR relies heavily on hospital discharge data, these cases fall through the surveillance net. An analysis by our group examined the utility of adding infant death certificates as a data source for identification of birth defects. Using data from the 1999–2006 FBDR cohorts, we found that the prevalence rate for cases of anencephaly increased from 0.44 to 0.79 per 10,000 live births when an infant death certificate with anencephaly was considered as a valid source of cases.[8]

Spina bifida is the most common NTD. It occurs when the neural tube fails to close along some portion of the spine, leaving the spinal cord and its membranes exposed. The opening must be surgically repaired. Individuals with spina bifida often have associated conditions such as hydrocephaly (water on the brain), clubfoot, mental retardation, muscle weakness/paralysis, loss of bladder and bowel control, as well as other complications.[1] Significant costs are coupled with these associated complications. A recent publication by Grosse et al. calculated the annual societal lifetime cost of a single spina bifida birth as $636,000.[9]

Over the last 10 years, the rate of spina bifida has decreased by 18% in Florida, from 3.63 per 10,000 live births in 1998 to 2.97 per 10,000 live births in 2007. In the early '90s, folic acid supplementation studies found

significant reductions in rates of NTDs with adequate supplementation prior to and early in pregnancy.[1] This prompted the United States Public Health Service to recommend all women of childbearing age consume 400 micrograms of folic acid every day. [10] The Food and Nutrition Board of the National Academy of Sciences Institute of Medicine (IOM) recommended women capable of becoming pregnant, take 400 micrograms of synthetic folic acid daily, from fortified foods or supplements or a combination of the two, in addition to consuming food with folate from a varied diet.[11] National and state educational campaigns, fortification of food, and supplementation efforts have played a large role in reducing the annual number of spina bifida cases in Florida from 92 in 1999 to 57 in 2006, which translates into direct and indirect cost savings of more than $22 million.[9]

Anencephaly

A comparison of race/ethnic-specific prevalence rates of NTDs using FBDR data shows no statistically significant differences among non-Hispanic (NH) whites (3.84 per 10,000 live births), NH-Blacks (3.65 per 10,000 live births), and all Hispanics (3.70 per 10,000 live births) (Figure 2). Differences in rates were observed when Hispanic subgroups were explored. From 1998–2007, infants of mothers of Puerto Rican ethnicity experienced the highest rates of anencephaly and spina bifida among Hispanic subgroups (5.40 per 10,000 live births) followed by those of Mexican ethnicity (4.65 per 10,000 live births). Prevalence rates for spina bifida and anencephaly among infants born to women of Puerto Rican ethnicity were significantly higher than for NH-Whites and NH-Blacks (p-value<0.05), while infants born to women of Cuban ethnicity experienced lower prevalence rates than NH-Whites (p-value<0.05).

Spina bifida

Using 1996 and 1997 Florida birth certificate data, variations in NTD rates among Hispanic subgroups were identified. No statistically significant difference was found between all Hispanics compared to NH-whites (6.6 per 10,000 vs. 6.4 per 10,000 live births), but differences did exist when Hispanic subgroups were explored individually. Births to mothers of Mexican ethnicity had the highest reported prevalence rate (9.5 per 10,000 live births) followed by Puerto Rican ethnicity (4.5 per 10,000 live births).[12] From 1998—2007, mothers of Puerto Rican and Mexican ethnicity experienced the highest NTD rates in their offspring but fluctuations have occurred annually so that neither subgroup has consistently maintained the highest rates (results not shown). More investigation is needed to examine expected rates within the Hispanic subgroups and untangle specific factors within the broad ethnic category of Hispanic. Nonetheless, Florida has a unique opportunity to analyze the distribution of particular birth defects by Hispanic subgroups, and to develop and evaluate focused intervention and prevention strategies.

Numerous studies have shown that the daily intake of folic acid decreases a woman's risk for having an NTD-affected pregnancy by up to 70%.[9,10] Women should take a daily multivitamin containing 400 micrograms of folic acid, in addition to maintaining a healthy diet. Since NTDs form early in pregnancy, often before a woman is aware that she is pregnant, and since half of all pregnancies in the U.S. are unintended, it is important that women of childbearing age consume this amount of folic acid at least two months prior to conception and throughout the first trimester of pregnancy.[10,11]

Images courtesy of the Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities.

Selected Birth Defects

Figure 3. Live birth prevalence rates of Down syndrome in Florida, by birth year, 1998–2007

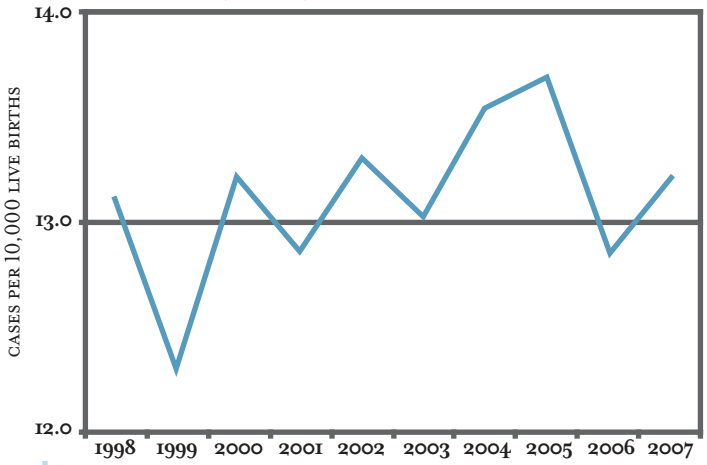
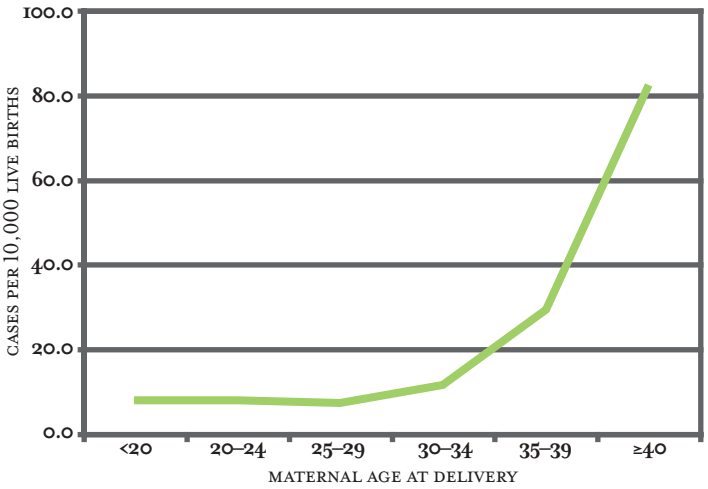


Figure 4. Live birth prevalence rates of Down syndrome in Florida, by maternal age at delivery, 1998–2007



Down Syndrome

Humans usually have 23 pairs of chromosomes, structures made of DNA that contain an individual's genetic information. Down syndrome is a common genetic birth defect caused by the presence of an extra copy of chromosome 21. This defect is associated with a myriad of clinical problems, including moderate to severe mental retardation,[1] decreased vision,[13] hearing loss,[13] congenital heart defects,[13,14] increased risk of obesity,[13,14] and increased risk for childhood leukemia.[14]

A dramatic increase in the prevalence rate of Down syndrome was observed with advancing maternal age (Figure 4). Women over 40 years of age have a 10-fold increased risk for delivery of an infant with Down syndrome compared to women under 30 (82.7 vs. 7.7 per 10,000 live births). Of the 3.5 million women of reproductive age in Florida, 35% are over age 35 and represent a high risk group; women in this age group had more than 33,000 births in 2007.[6]

While the cause of the chromosomal error is unknown, early detection is important to improve the quality of life outcomes in affected pregnancies and to receive early intervention services for medical and developmental skills.[1]

Congenital Heart Defects

Collectively, congenital heart defects (CHDs) comprise the largest group of congenital anomalies, and are the leading cause of birth defect-related deaths.[2] Using a national database of hospital inpatient stays; Russo et al found that of all hospitalizations for which a birth defect was the principal diagnosis, 33.5% were related to cardiac or circulatory anomalies, with $1.4 billion spent nationally for hospitalizations in 2004.[16]

Coarctation of the aorta occurs when the large artery that sends blood from the heart to the rest of the body is too narrow. Surgery or angioplasty is needed to widen the section of the artery restricting blood flow.[17] In Florida, coarctation of the aorta occurs at a rate of 6 cases per 10,000 live births. National estimates are presently unknown. Hoffman et al. report that this abnormality is frequently missed by physicians and many patients are usually diagnosed later in life.[18]

Tetralogy of Fallot (TOF) and transposition of the great arteries (TGA) are structural anomalies that result in decreased circulating oxygen levels in the blood. TOF is a combination of four structural heart defects which present together and TGA occurs when the arteries that move oxygenated blood are switched.[1] Nationally, these anomalies appear in 3.9 per 10,000 and 4.7 per 10,000

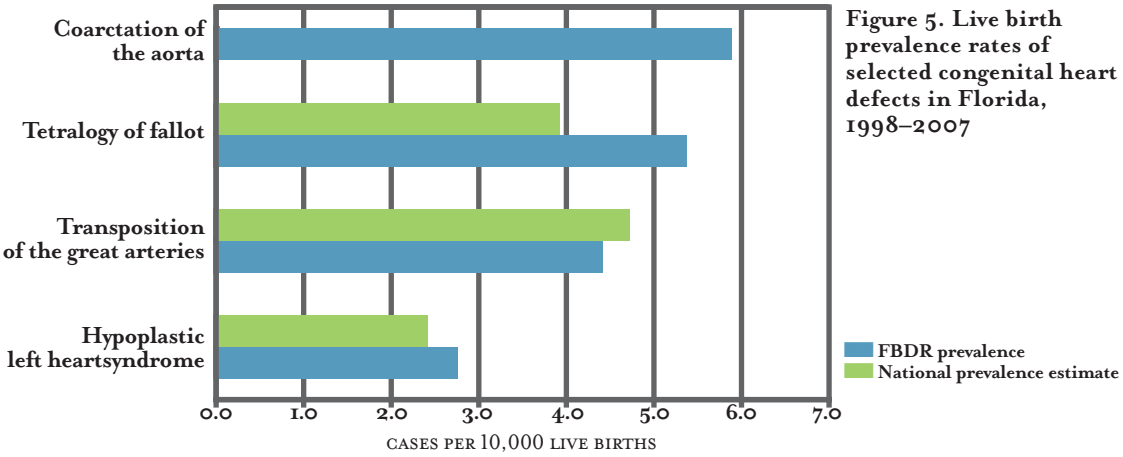
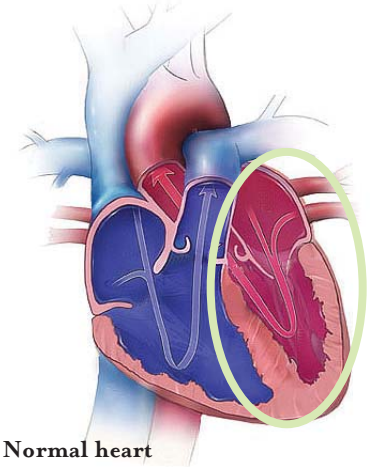
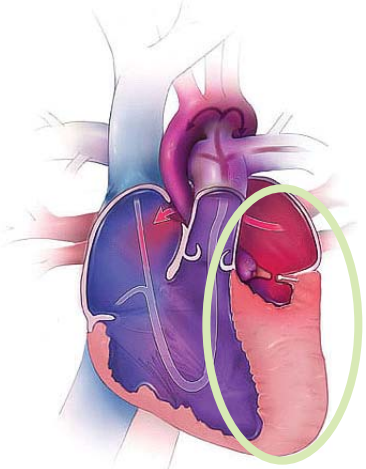


Figure 5. Live birth prevalence rates of selected congenital heart defects in Florida, 1998–2007



Normal heart



Hypoplastic left heart syndrome

Images courtesy of the Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities.

live births, respectively.[7] Florida's reported prevalence rate for TOF is higher than the national estimate, (5.33 vs. 3.9 per 10,000 live births, p=0.0002), and was observed more frequently in non-Hispanics, 5.65 per 10,000 live births compared to 4.38 per 10,000 live births for Hispanics. The overall TGA rate (4.39 per 10,000 live births) was similar to the national rate.

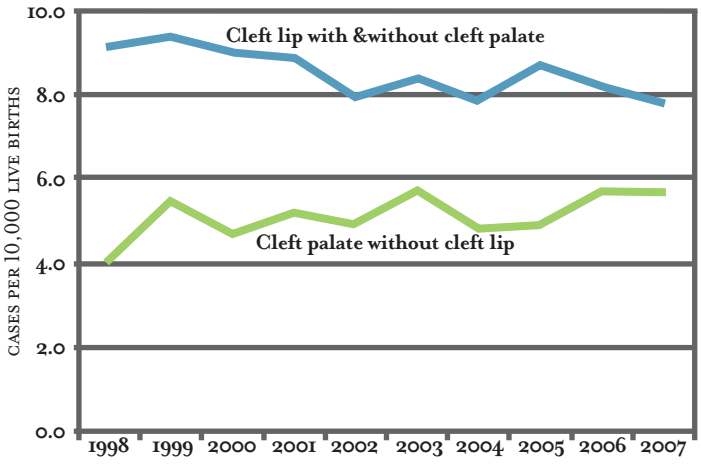
Hypoplastic left heart syndrome (HLHS) is a term used to describe an underdeveloped left side of the heart, and is a condition where the heart is unable to provide enough blood flow to the body.[1] National prevalence rates for HLHS are 2.4 per 10,000 live births, similar to the rate in Florida, 2.75 per 10,000 live births.[7]

The variations noted between national and Florida prevalence rates may be attributed to differences in case definition and case ascertainment methodologies. In a large study using pooled data from 11 active statewide surveillance systems, Canfield and colleagues (2006) were able to compare those pooled average prevalence rates to prevalence rates obtained from passive systems. Among the CHDs examined in their report, TOF and HLHS were overestimated in the passive systems. However, TGA prevalence rates were underestimated, 3.57 vs. 4.74 per 10,000 live births.[7] These patterns are the same as those reported by the FBDR and can be explained by the inclusion criteria and the passive nature of the registry. The current inability of the FBDR to confirm diagnosis of defects and its reliance on administrative ICD-9-CM codes may increase specific rates by including potentially false positive diagnoses. Alternatively, underestimation of rates is likely to occur in the FBDR due to limiting the case definition to only include live births, compared to national pooled data estimates that include stillbirths and terminations.

There are maternal factors that may increase the risk of having a pregnancy affected by a CHD. Some factors that have been shown to have the greatest risk for a CHD-affected pregnancy include contracting a viral infection (such as rubella or influenza),[1] exposure to certain chemicals, such as tobacco smoke,[19] or taking anti-seizure or anti-depressant medications.[20] Mothers with pre-pregnancy obesity and/or diabetes that are not under adequate control are also more likely to have a baby with a CHD.[19, 21] Women with low folic acid levels in blood during the prenatal period, due to either poor diet or inadequate consumption of prenatal vitamins containing folic acid, are also at increased risk.[1]

Orofacial cleft

Figure 6. Live birth prevalence rates of orofacial clefts in Florida, by year, 1998–2007



Orofacial Clefts

Cleft lip and cleft palate are the two most common forms of craniofacial defects. These types of clefts occur when the structures of the mouth fail to form properly. This typically occurs early in fetal development between four and ten weeks after conception. Cleft lip and palate may occur separately or together. A cleft lip involves the space between the upper lip and the nostrils, and clefts of the palate may occur in the front of the palate, which involves underlying bone, or in the back area involving soft tissue. Infants born with a cleft typically undergo surgery and receive speech therapy and orthodontic care.[1]

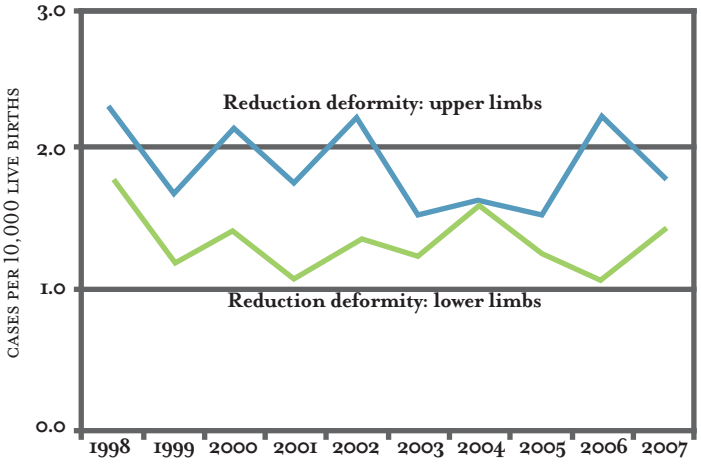
National rates of orofacial clefts, from 1999–2001, are 10.5 per 10,000 live births for cleft lip with and without cleft palate and 6.4 per 10,000 live births for cleft palate without cleft lip.[7] The rate of cleft lip with and without cleft palate for Florida was 8.50 per 10,000 live births and has been decreasing over the last 10 years with an average annual percent change of -1.67% (p-trend=0.006). The overall rate of cleft palate without cleft lip was 5.13 per 10,000 live births and although Figure 6 implies a slightly increasing trend for cleft palate without cleft lip rates over the same 10-year period, the annual trend was not statistically significant.

Using data from Massachusetts, Weiss et al. attempted to estimate some costs associated with orofacial clefts. The mean cost of hospitalizations associated with orofacial clefts from birth to two years of age for each case was $21,090; conversely, the mean cost for hospitalizations among infants without craniofacial defects was $2,504.[22]

Pregnant women who smoke are significantly more likely to have an infant born with cleft lip or cleft palate. Reported odds ratios after adjustment for folic acid, obesity, alcohol use, maternal age, education , and race/ethnicity, range from OR=1.3 (95% CI:1.0-1.6), for periconceptional maternal smoking and cleft lip with or without cleft palate, to OR=4.2 (95% CI:1.7-10.3), for heavy maternal smokers with bilateral cleft lip and palate.[23,24] In 2005, 17.9% of Florida Pregnancy Risk Assessment Monitoring System (PRAMS) respondents reported smoking during the three months prior to getting pregnant.[25] Other literature examines potential risk factors including maternal occupational pesticide exposures (OR=1.37, CI=1.04, 1.81).[26]

Images courtesy of the Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities.

Figure 7. Live birth prevalence rates of limb reductions in Florida, by year, 1998–2007



Limb Reduction Defects

Limb defects are relatively rare in comparison to other birth defects. However, an infant born with a limb malformation is easily identified at birth because the physical abnormality is so apparent. If part of or the entire arm or leg does not form completely during the pregnancy, the infant is diagnosed with a limb reduction defect. This is a broad category of defects, ranging from the complete absence of the limb (amelia) to a shortened, but still present and functional limb. The difficulties experienced by an infant affected with a limb reduction varies based upon the severity, the location, and size of the defect, and may limit daily activities.[1] Lifetime costs for infants born with lower and upper limb defects were estimated to average $199,000 and $99,000, respectively, and are attributed to the need for prosthetics, orthotics, and/or rehabilitation,[15] with most severe cases, such as amelia, requiring much higher expenditures.

Nationally, upper limb reductions occur more frequently (3.8 per 10,000 live births) than lower limb reductions (1.9 per 10,000 live births).[7] Observed prevalence rates in Florida for upper reduction defects were 1.88 per 10,000 live births and 1.35 per 10,000 live births for lower limb reduction defects. In Florida, limb reduction defects are rare, and their low case counts contribute to the relative instability of annual rates.

Compared to national rates, the lower rates of limb reductions in Florida may be attributed to differences in case definitions, particularly the fact that national estimates rely on programs that include pregnancy terminations and/or stillbirths that are actively ascertained. Severe cases that result in fetal death are not counted in Florida, but are considered as cases in the national estimate.

Causes of limb reductions are unknown, but some risk factors have emerged in the literature. Waller et al. performed an analysis to identify associations between maternal obesity and congenital anomalies. The authors found a slight increased risk of limb reductions in mothers with an obese pre-pregnancy body mass index (BMI) (≥30), OR=1.34 (95% CI, 1.03-1.73), when compared to women with a pre-pregnancy BMI value greater than or equal to 18.5 and less than 25.0, as recommended by the World Health Organization (WHO).[27] Women should take steps to achieve a healthy lifestyle through diet and exercise. Maternal smoking has been associated with a 25% increased risk of all types of limb reduction defects.[28] Additionally, avoiding and/or minimizing exposure to chemicals and infections may decrease risk for limb defects.[1]

Lifetime costs for infants born with lower and upper limb defects were estimated to average $199,000 and $99,000, respectively, and are attributed to the need for prosthetics, orthotics, and/or rehabilitation, with most severe cases, such as amelia, requiring much higher expenditures.

Gastroschisis

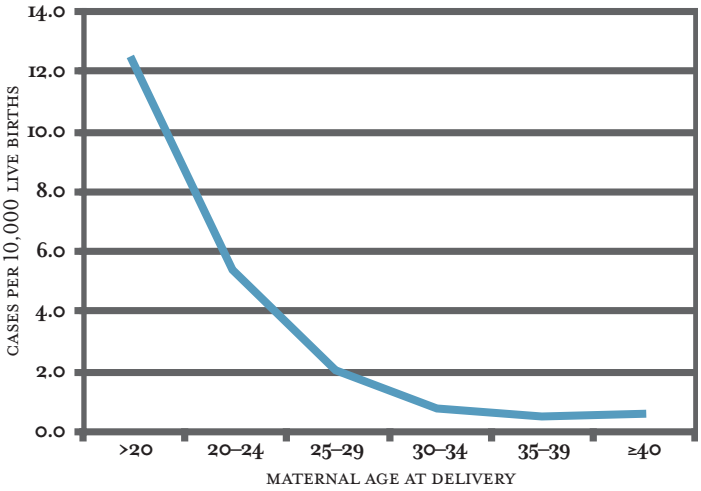
During fetal development, the intestines form in the umbilical cord and then move inside the abdomen. Gastroschisis is a herniation of the small intestines, part of the large intestines, and occasionally the liver and spleen.[1] Associated costs of repair can be substantial; $108,000 in 1992 for each new case.[15] Once repaired, children may have problems moving digested food, but survival rates are high.

A prevalence rate of 3.71 per 10,000 live births was identified nationally, and was consistent with the Florida overall rate of 3.51 per 10,000 live births. Canfield et al. reported that NH-Black mothers experienced a reduced risk of having a gastroschisis-affected pregnancy, compared to NH-White mothers (PR=0.65; 95% CI, 0.52-0.82).[7] In Florida, we identified a similarly reduced risk for NH-Black mothers (PR=0.40; 95% CI, 0.32-0.50). Recently, we also reported that women born outside of the U.S. were less likely to deliver an infant affected with gastroschisis, compared to U.S.-born women (PR=0.59; 95% CI, 0.41-0.86).[29] The underlying mechanism of this finding is unknown.

Figure 8 shows the increased prevalence rate for gastroschisis-affected pregnancies among teenage mothers, a high risk group. Pregnancies to women less than 20 years of age had a gastroschisis prevalence rate of almost 13 per 10,000 live births. Women under 20 years of age experience a 10-fold increase in risk of a gastroschisis-affected pregnancy compared to women over 25 (PR=10.3, p-value<0.0001).

Gastroschisis is suspected to have an environmental link; however, Root et al. was unable to identify any statistically significant association between gastroschisis affected pregnancies and potentially contaminated drinking water from textile mills in North Carolina.[30] Waller et al. reported a possible association between the agricultural chemical atrazine and gastroschisis-affected pregnancies. An odds ratio of 1.6 was found for maternal residence <25 km from a toxic atrazine site.[31] Tobacco smoke, malnutrition, and low BMI have also been suggested as risk factors for gastroschisis.[31]

Figure 8. Live birth prevalence rates of gastroschisis in Florida, by maternal age group, 1998–2007



Gastroschisis

Images courtesy of the Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities.

Figure 9. Live birth prevalence rates of pyloric stenosis in Florida, by infant sex, 1998–2007

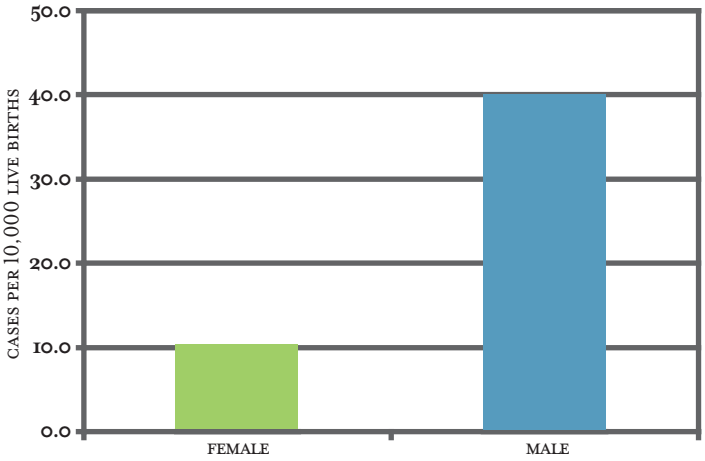


Table 2. Percentage of alcohol use and binge drinking reported during the third trimester in Florida mothers by PRAMS, 2005.[25]

MATERNAL DEMOGRAPHIC	% OF WOMEN REPORTING ALCOHOL USE DURING PREGNANCY	% OF WOMEN REPORTING BINGE DRINKING DURING PREGNANCY
OVERALL	7.3	0.4
MATERNAL AGE		
19 and younger	1.8	0.6
20–24	6.4	0.7
25–34	6.5	0.1
35 and older	15.7	1.0
RACE/ETHNICITY		
Non-Hispanic White	9.1	0.0
Non-Hispnaic Black	6.1	0.9
Hispanic	5.1	0.8
EDUCATION		
Less than 12 years	5.3	0.8
12 years	5.2	0.4
More than 12 years	9.7	0.3
HOUSEHOLD INCOME		
$15,000 or less	5.7	0.3
$15,000–$34,999	6.0	0.9
$35,000 or more	10.5	0.2
MARITAL STATUS		
Married	8.0	0.3
Not married	6.3	0.6

Pyloric Stenosis

The digestive process requires food from the stomach to empty into the small intestine. In some cases, the valve that performs this operation, the pylorus muscle, is thickened and prevents normal digestion. This condition is called pyloric stenosis. Infants typically present with forceful vomiting after feedings, beginning at 3 weeks of age. Pyloric stenosis occurs more frequently in male infants and carries a genetic component.[33]

The 1998—2007 prevalence rate of pyloric stenosis in Florida was 25.3 per 10,000 live births. Although the prevalence is very high compared to other defects described in this report, following surgical repair, further morbidity is rare. As suggested in the literature, rates of pyloric stenosis differ according to infant sex,[34] with males having four times greater risk than female infants (PR=3.9, p-value<0.0001). Currently, no comparative national estimates are available and causes of pyloric stenosis are largely unknown.

Fetal Alcohol Spectrum Disorders

Consumption of alcohol during pregnancy is a risk factor for poor birth outcomes and the cause of fetal alcohol spectrum disorders (FASD).[35] FASD is an umbrella term that covers specific conditions, which range from mild to severe and may present in a variety of ways: physical features, structural anomalies, central nervous system (CNS) and behavior abnormalities.[36] The most severe is fetal alcohol syndrome (FAS), the leading known cause of preventable mental retardation.[36, 37] Other conditions include alcohol-related birth defects (ARBD), and alcohol-related neurodevelopment disorder (ARND).

Since no uniform feature, biochemical, chromosomal, or pathologic characteristic exists for diagnosis of FAS, a scoring system was developed to assess presence of a FASD. This system weighs evidence of maternal alcohol exposure, infant facial anomalies, growth retardation, congenital anomalies, and CNS neurodevelopmental abnormalities to classify the disorder as FAS (3 categories), ARBD, or ARND.[38] Distinct physical features include short palpebral fissures, thin upper lips, flat midface, low nasal bridge, and pre and post natal growth retardation not caused by poor nutrition. Congenital anomalies associated with alcohol exposure include cardiac, skeletal, renal, ocular and auditory defects.[26, 38, 39] Associated CNS abnormalities consist of small cranial size, structural brain conditions (i.e. microcephaly), developmental delay of age appropriate skills (i.e. motor skills, hearing loss, poor coordination).[36, 38] Additional behavioral/cognitive abnormalities may result from alcohol exposed pregnancies, such as, attention and

The U.S. Surgeon General has stated clearly that no amount of alcohol consumption can be considered safe for a pregnant woman and that alcohol can damage a fetus at any stage of pregnancy.

Fetal alcohol spectrum disorders (FASDs) cause a range of lasting medical and developmental problems and result in economic losses of billions of dollars.

—A Call to Action: A Report of the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effects

memory deficits, hyperactivity, and poor impulse control.[38, 40] This complex list of resultant conditions is a recipe for long-term care expenses. Considering special education, health care needs, and therapy for cognitive and/or behavior disorders, the Substance Abuse and Mental Health Services Administration (SAMHSA) recalculated Harwood and Napolitano's 1980 individual lifetime cost of FAS for 2002, accounting for rising health care costs and inflation. This estimate, excluding lost productivity, was $1.6 million per person.[41]

During the 1980s and 1990s, May et al. estimated that the FAS prevalence in the United States ranged from 5–20 cases per 10,000 live births; if ARBD and ARND were included in the case definition the rate rose to 1 per 100 live births.[40] The differences observed in the prevalence estimates raise several concerns for FASD surveillance activities. First, FASD case ascertainment is greater among birth defect surveillance programs with longer periods of time between birth and defect diagnosis.[42] For example, FASD diagnosis criteria are most easily detected between age 2 and 11,[40] particularly for the ARND cognitive and behavioral symptoms, thus a birth defect surveillance system that requires defect diagnosis within the first year of life would miss a significant proportion of FASDs, compared to a program that follows the child until age 3 or age 5. In addition, differences in methods of FASD ascertainment can influence prevalence rates within a state program. Druschel and Fox (2007) found prevalence rate discrepancies (0.90 per 1000 live births vs. 0.21 per 1000 live births) between two counties in New York State with similar demography. Their investigation discovered the cause of this discrepancy to be an active clinician that educated health care providers on FASDs in the higher rate county.[40] Furthermore, collection of information on maternal alcohol consumption, if able to be obtained at all, is subject to recall bias.[38] Taking into consideration that the diagnostic criteria of four out of the five FASD conditions require evidence of maternal alcohol exposure,[36] accurate assessment of maternal alcohol consumption influences prevalence rates of FASDs.

Due to these methodological concerns, reliable prevalence rates specific for Florida are currently unknown. However, the Pregnancy Risk Assessment Monitoring System (PRAMS) data help to estimate alcohol use among pregnant women. In 2005, 7.3% of Florida women used alcohol during the last trimester of their pregnancy, and 0.4% participated in binge drinking behavior during this time period.[25] Women who reported the highest percentage of alcohol consumption while pregnant were NH-White women, women over 35 years old, women with a post-high school education, married women, and women with a household income greater than $35,000. However, a different pattern was observed among "binge" drinkers; they were more likely to be NH-Black women, women with less than 12 years of education, women with household income greater than $15,000 but less than $35,000, and unmarried women.[25]

FASD is 100% preventable. Primary prevention and intervention strategies need to be implemented to reduce alcohol consumption among pregnant women and increase support programs for heavy drinkers and affected children.

Teratogens

Sixty-five percent of congenital abnormalities are of unknown cause, and are thought to involve a complex interaction between genetics and the environment.[4, 43]

The field of teratology studies birth defects and is challenged with assessing the ability of a chemical, drug, physical factor, gene mutation, or virus to produce congenital defects in humans.[44] The underlying hypothesis is that prevention of the defect may be achieved by reduction and/or limiting exposure to the agent, compared with altering gene function.[45] For many years it was thought that the placenta protected the developing embryo/fetus from physiological harm. In the 1940s, Gregg discovered that German measles caused congenital abnormalities, and in 1961 Lenz showed that in-utero exposure to thalidomide caused absence of extremities, demonstrating that the placental barrier was permeable.[45]

The embryonic period occurs from the 3rd to 8th week of gestation, and is characterized by organogenesis.[44] Each system or organ has a critical period of development. Teratogen exposure may produce a congenital anomaly at one time period and produce no defects in another time period.[46] This variability combined with the rarity of these conditions (small numbers and low statistical power) complicate teratology research.[46] Due to the small numbers of cases of specific defects available for research, defects are often lumped together for study.[46] This methodology may obscure associations of etiology and pathogenicity.[46] Additionally, estimating the dose of teratogen exposure to the embryo or fetus is an approximation at best, and is usually estimated through maternal exposure. Specific methodological obstacles exist for each teratogenic exposure; a discussion of some suspected teratogens follows.

Many serious birth defects occur during the embryonic period, the 3rd to 8th week of gestation, before a woman knows she is pregnant. Planning for a healthy pregnancy can reduce the occurrence of some birth defects.

Environmental Contaminants

Chemicals known or suspected to cause harm to embryo/fetal development can be found in occupational settings: farming, chemical plants, refineries, and in the environment in water, air, and soil. Love Canal is an example of an environmental contamination and its consequences to public health. In the 1920s, Love Canal, an area near Niagara Falls, New York, became a chemical disposal site for several industries and the city.[47, 48] For 25–30 years, unknown kinds and quantities of chemicals were dumped there and subsequently covered with earth in 1953. A residential community and a school were built over this landfill. In the '70s, residents began complaining of chemical odors in basements. After periods of heavy rain, waste-disposal drums were unearthed, puddles of noxious substances could be seen, and children returning from play would have burns on their hands and faces.[47, 48] In 1978, the reproductive health effects detected in 97 resident families included increased miscarriages (OR=1.49) and five children with birth defects.[48] Ultimately, residents were relocated due to this "medical emergency" while clean-up and environmental sampling continued.

Research on environmental contaminants and birth defects is limited by the inability to isolate the effects of each chemical in the environment on human development. There are currently many articles relating the effect of "pesticides" or "air pollution" on reproductive outcomes. The issue with these terms is that each contamination is filled with a myriad of chemical compounds. In order to isolate the teratogenic effects of individual compounds, this field of research draws information from toxicology,

animal, and occupational studies to estimate health effects associated with specific chemical exposures.[46]

Another limitation to studying environmental contaminants is obtaining accurate measurements of exposure. Frequently in epidemiology studies, proximity of residence to a contamination site or geographic informational software is used to estimate exposure. However, using drinking water exposure as an example, some residents may consume local water for drinking, while others purchase water, while still others have installed filtration systems in their homes. Therefore, each resident has different levels of exposure that is not accurately measured by proximity of residence to a waste site. The Environmental Working Group (EWG) examined umbilical cord blood of 10 babies born in August and September of 2004 for presence of toxic chemicals. On average, 200 toxic compounds were found in the infant cord blood.[49, 50] Specifically mercury, polycyclic aromatic hydrocarbons (PAHs), polybrominated dioxins and furans (PBDDs/Fs), perfluorinated chemicals (PFCs), chlorinated pesticides, polybrominated diphenyl ethers (PBDE), polychlorinated napthalenes (PCNs), and polychlorinated biphenyls (PCBs), were identified. Other studies have tested infant meconium and detected organophosphate pesticides.[49]

The limitations addressed above have resulted in few studies showing any association between birth defects and environmental contaminants. The research that does exist is not widely agreed upon. Brief descriptions of current environmental exposure research topics are presented below.

The blood brain barrier is not yet present in a developing fetus, thus the fetus is more susceptible to heavy metal and the associated neurological deficits.

Heavy Metals

Mercury and lead occur naturally in the land and air we breathe.[51] Concentrations of mercury are increased by certain industrial processes. Once mercury is vaporized it falls back to the earth and builds up in water sources. Pregnant women are primarily exposed to this metal by consumption of fish that absorb mercury from their surroundings.[52] Similarly, lead exposure occurs through ingestion of contaminated food and drinking water.[51] The blood brain barrier is not yet present in a developing fetus, thus the fetus is more susceptible to heavy metal and the associated neurological deficits.[44,49,51,52]

Nitrates

Nitrate is an inorganic ion that is used primarily in agricultural areas as a fertilizer.[51] A literature review by Manassaram et al. on nitrate exposure and pregnancy outcomes identified several articles examining the relationship of nitrate consumption and birth defects. One study examining this relationship and neural tube defects among California resident mothers assessed exposure through sampling of ground water, as well as administering a beverage and dietary questionnaire.[53, 54] The results were non-significant (OR=1.9, 95% CI 0.73-4.7).[53, 54] Closer examination of risk for anencephaly and spina bifida separately, revealed a significantly increased risk for anencephaly alone, OR=4.0, 95% CI (1.0-15.4).[53, 54] Another study by Mattix et al. used natality data to obtain rates of abdominal wall defects among Indiana residents and U.S. geological survey data for surface water nitrate levels. This study found no significant correlation between the nitrate levels during the month of conception and rates of abdominal wall defects.[55]

The health effects of air pollution in relation to congenital defects have been of recent interest, but conflicting evidence is reported.

Pesticides

Exposure to high levels of pesticides, through contaminated drinking water, food, and occupational contact, may increase the risk for some congenital defects. Earlier we noted that occupational pesticide exposure was associated with increased risk of orofacial clefts (OR=1.37 (95%CI: 1.04-1.81).[26] Brender et al. examined maternal pesticide exposure and influence on NTD prevalence. They interviewed Mexican American woman about their environmental and occupational exposure to pesticides during the preconceptional period. Pesticide use in homes or yards, and close proximity to cultivated fields were related to increased odds ratios of 2.0 and 3.6, respectively.[56]

Air Pollution

The health effects of air pollution in relation to congenital defects have been of recent interest, but conflicting evidence is reported. In a Texas stationary air monitoring study, statistically significant associations between carbon monoxide levels and tetralogy of Fallot (OR=2.04), particulate matter levels and atrial septal defects (OR=2.16), and sulfur dioxide levels and ventricular septal defects (OR=2.16) were observed.[57] However, research performed in Atlanta observed only one statistically significant association between increased particulate matter and patent ductus arteriousis (OR=1.60).[58] Another study in southern California identified a dose-response relationship for increasing carbon monoxide exposure during the second month of gestation with cardiac ventricular septal defects; odds ratios ranged from 1.62 (95% CI: 1.05, 2.48) for the second quartile to an odds ratio of 2.95 (95% CI: 1.44, 6.05) for the fourth quartile.[59] Differences in study results may be partially explained through the different methods used for air sampling techniques; personal monitors, stationary monitors; as well as the difficulty isolating specific components of the pollution.[60]

Radiation

Ionizing radiation is both a teratogen and mutagen (capable of altering genes).[44] Exposure to diagnostic radiation (i.e. x-rays) is associated with prenatal death, growth retardation, congenital anomalies, mental retardation, and microcephaly. As with other teratogens, production of a birth defect is dependent upon when exposure occurs in the gestational period and dose of radiation.[61, 62] The risk of birth defects among female veterinarians is increased with occupational high exposure to radiation, measured as >10 x-rays week, OR=5.73, 95% CI: 1.27-25.80).[63] The risk significantly increases at levels above 15 rads.[45, 61] Standard diagnostic procedures, such as x-rays or computed tomography scans expose the fetus to approximately 5 rads.[61]

Teratogens

Phenylketonuria (PKU)

High maternal blood levels of phenylalanine, a condition known as phenylketonuria (PKU), during pregnancy is associated with increased risk of mental retardation, microcephaly and cardiac defects to the fetus.[44, 52] However, among women with PKU, significant reduction in risk of CHDs is reported in pregnancies when dietary modifications are made prior to conception.[64] When preconception dietary changes were implemented, only 2% of infants had a CHD, compared to 17% when dietary modifications were made during pregnancy.[64, 65] Monitoring the level of maternal phenylalanine is also important for reducing CHD pregnancy outcomes. Malaton et al. dichotomized women with phenylalanine levels less than and greater than 600 µmol/L at 8 weeks gestation; only women with phenylalanine levels >600 µmol/L had an infant born with a CHD.[64, 66]

Women with uncontrolled pregestational diabetes are three to four times more likely than non-diabetic women to have pregnancies with congenital anomalies.

Maternal Diabetes

Women with uncontrolled pregestational diabetes are three to four times more likely than non-diabetic women to have pregnancies with congenital anomalies.[44, 52] Macintosh et al. studied congenital anomalies among births to women diagnosed with pregestational type 1 or type 2 diabetes in England, Wales, and Northern Ireland. Risk of major congenital anomalies in pregestationally-diagnosed women was 2.2 (95% CI: 1.8 to 2.6); this estimate includes stillbirths and terminations.[67] Analysis of birth certificate information among Washington state residents with a pregnancy outcome of hypospadias and maternal pre-existing diabetes diagnosis revealed an OR=2.2, compared to women without a diabetes diagnosis.[68] CHDs, specifically transposition of the great vessels, atrioventricular septal defects, and HLHS, have also been associated with pregestational diabetes.[69] However, glycemic control prior to conception and during pregnancy has been shown to reduce CHD risk to the levels of the general population.[69]

Infections

Congenital rubella syndrome (CRS) is a combination of congenital heart defects, cataracts, and deafness.[44] The cause of this syndrome is maternal infection with German measles. In the '70s the Measles, Mumps, and Rubella (MMR) vaccination program began and in 2004 CRS was declared to be eliminated from the United States.[70] However, continued surveillance of these infections and increased education of the importance of childhood vaccines are critical to maintaining healthy birth outcomes and population immunity. Each year one in 750 children develop disabilities including mental retardation as a result of cytomegalovirus (CMV) infection.[1] Precautions should be taken to decrease risk of infection by practicing good personal hygiene. Herpes simplex-associated abnormalities are rare and usually transmit as a venereal disease to infants during delivery. Human immunodeficiency virus (HIV) appears to have a low teratogenic potential.[44] Syphilis may also be transmitted transplacentally and produces adult pathological findings in the fetus, such as blindness and skin lesions.[45]

Limitations

Many things we need can wait; the child cannot. Now is the time his bones are being formed, his blood is being made, his mind is being developed. To him, we cannot say, tomorrow. His name is today.

Gabriela Mistral—Educator, Diplomat, and Poet (Chilean Nobel Laureate)

The interpretation and comparison of the information presented in this report requires a discussion of the FBDR's current case-finding approach and its potential impact on the completeness and accuracy of its data. First, the FBDR's case definition is restricted to live births. The exclusion of other pregnancy outcomes, including stillbirths and spontaneous or elective terminations of pregnancy (TOPs), may result in underestimated prevalence rates, particularly for defects in which a large proportion of cases result in fetal mortality (e.g. anencephaly). Knowledge of other state-based surveillance systems inclusion criteria is needed for appropriate comparison of prevalence rates. Second, the FBDR ascertains cases diagnosed through the first year of life. Prevalence rates for defects diagnosed at birth or early in life (e.g. limb reduction defects) should be comparable to other state-based surveillance programs. However, we caution comparison of our rates to programs with longer ascertainment periods, particularly when assessing defects frequently identified after the first year of life (e.g. certain CHDs, FASD). Third, the linkage algorithms employed by the FBDR require that the infant's birth certificate be able to be matched to administrative datasets, and this is often highly dependent upon the mother and/or infant having a social security number (SSN). This has the potential to result in a disproportionately higher degree of underascertainment among subsets of the population that are more likely to have inaccurate or missing SSNs (i.e. immigrants, minorities). Lastly, the use of these administrative data sources not created for the purposes of a birth defects registry requires that a record exist. For infants born with likely fatal defects (e.g. anencephaly, trisomy 18), the infant may expire prior to a hospital discharge record even being created and, in turn, is likely to fall through the current FBDR's surveillance net.

The passive FBDR also presents challenges for case sensitivity and specificity. This passive surveillance system lacks the ability to verify and appropriately document birth defect diagnoses through medical record review and abstraction. As mentioned previously, administrative datasets used were not designed with the expressed purpose of creating a birth defect surveillance registry. Relying solely upon reported ICD-9-CM codes without case confirmation may result in misclassified, non-specific, and false-positive diagnoses. Problems with non-specificity are exemplified in the diagnosis of gastroschisis and omphalocele, which until October 2009 were recorded using the same ICD-9-CM diagnosis code, 756.79. Although the registry implemented a way to differentiate these anomalies using a "repair of gastroschisis" procedure code, it is a suboptimal approach. False positives in the FBDR may arise when there are coding or diagnosing errors. The ICD-9-CM code used for identification of defects depends on the physician's assessment and documentation in the medical record, a coder's interpretation of the physician's notes, and the coder's accurate entry of each code. For example, a medical coder may interpret a notation for maternal alcohol use during pregnancy as fetal alcohol syndrome when the manifestation of the actual defect was never diagnosed or noted in the medical record.

Another important aspect of a birth defect surveillance system is the timeliness of data. Due to the registry's reliance on the acquisition, preparation, and linkage of source datasets, the final inventory of affected infants and dissemination of prevalence rates lags two years behind present time. This has impacted implementation of effective primary and recurrence prevention programs and timely referral to services.

Strengths

The FBDR seeks to prevent birth defects through:

- **Public health surveillance, data dissemination, and public health action**
- **Translation of complex scientific findings into data driven prevention activities**
- **Community investigations and epidemiological studies.**

Despite the limitations, the FBDR constitutes a statewide, population-based, cost-effective registry to identify infants with birth defects within a large, multiethnic population. The CDC has estimated that national costs for a passive birth defects surveillance system without any follow-up are approximately $5 per live birth; for Florida that would result in a budget of nearly $1.1 million. Florida's current budget for a birth defects registry is one tenth of the estimated resources, $129,036 or $0.56 per live birth. The FBDR is able to fulfill its mission to the people of Florida by responding to inquiries and concerns at the local level. Due to its large number of cases and unique population characteristics, Florida is able to contribute substantially to various national collaborative projects, including those on NTDs, pyloric stenosis, and race and defect-specific prevalence estimates reported by the NBDPN annual report. Through the provision of data and consultation, the FBDR plans to help entities such as CMS and the Florida Department of Education (FDOE) anticipate resources that will be needed to assist infants and children with birth defects in upcoming years. Additionally, FBDR surveillance data assist public health professionals in targeting those areas and populations in which primary prevention strategies would make the largest difference in the lives of children and families, ultimately saving costs to the state.

The FBDR contributes important data on the health and well-being of Florida's infants. Birth defects are the leading cause of infant mortality, contributing to long-term disability and developmental problems. Data are used by state and national health agencies to identify, investigate and prevent birth defects. Accurate, complete and timely data are essential for designing and evaluating birth defects prevention programs. For example, in Florida our birth defects data identified that women of Hispanic ethnicity have a higher risk for giving birth to an infant with NTDs such as anencephaly and spina bifida. Working collaboratively with numerous partners the department was able to secure funding to support the purchase and distribution of multivitamins with folic acid to women across Florida. Culturally and linguistically appropriate educational materials were developed and distributed to health care providers serving Florida's women and have served as models for prevention programs in other states and at the CDC.

The Department of Health is the only agency in Florida with authority to create confidential disease registries in accordance with s. 381.0031, F.S. Although information on birth defects can be found in multiple data sets, the FBDR is the only data source where data are combined with other demographic, clinical and maternal and child health information for analysis and reporting on the occurrence of birth defects in Florida. Data on trends, risk factors, costs, access to services, and effectiveness of prevention programs are analyzed and interpreted at the county and state level for use by health policy leaders, county health departments, Healthy Start Coalitions, child health advocates, health care providers and researchers.

Future Directions

The FBDR has been the primary source of birth defects data in Florida for over a decade. Through its website, www.fbdr.org, the state is able to disseminate important epidemiologic data and research findings, and expand knowledge of known and currently unknown risk factors and causes of birth defects to the general public. The FBDR continues to strive for improved data quality with ongoing evaluation of existing procedures and the pursuit of enhanced approaches. The FDOH participates in several other birth defect projects, including the Environmental Public Health Tracking (EPHT) initiative, and is the recipient of a CDC cooperative agreement to improve its surveillance, education, and referral activities, and to reach out to vulnerable populations, including refugees. Future plans include linking birth defects data with environmental data and other maternal/child health data sets to explore other known risk factors such as diabetes, obesity, smoking, alcohol, family history, medication use, drug use and maternal infections during pregnancy.

Appendix I

Publications Associated with the FBDR Consortium

Salemi JL, Tanner JP, Block S, Bailey M, Correia JA, Watkins SM, Kirby RS. The relative contribution of data sources to a birth defects registry utilizing passive multi-source ascertainment methods: Does narrowing the birth defects case ascertainment net lead to overall or disproportionate loss? Journal of Registry Management. (Under Review).

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Salemi JL, Pierre M, Tanner JP, Kornosky JL, Hauser KW, Kirby RS, Carver JD. Maternal nativity as a risk factor for gastroschisis: A population-based study. Birth Defects Res A Clin Mol Teratol. Jul 30 2009.

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Nembhard WN, Wang T, Loscalzo ML, Salemi JL. Variation in the Prevalence of Congenital Heart Defects by Maternal Race/Ethnicity and Infant Sex. J Pediatr. Oct 7 2009.

Nembhard WN, Salemi JL, Wang T, Loscalzo ML, Hauser KW. Is the Prevalence of Specific Types of Congenital Heart Defects Different for Non-Hispanic White, Non-Hispanic Black and Hispanic Infants? Matern Child Health J. Jan 24 2009.

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Cui W, Ma CX, Tang Y, Chang V, Rao PV, Ariet M, Resnick MB, Roth J. Sex differences in birth defects: a study of opposite-sex twins. Birth Defects Res A Clin Mol Teratol. Nov 2005;73(11):876–880.

Hauser KW, Lilly CM, Frias JL. Florida health care providers' knowledge of folic acid for the prevention of neural tube defects. South Med J. May 2004;97(5):437–439.

Roth J, Figlio DN, Chen Y, Carter RL, Ariet M, Resnick MB, Morse SB. Maternal and infant factors associated with excess kindergarten costs. Pediatrics. 2004;114(3), 720–728.

Williams CA, Mardon RE, Grove D, Wharton P, Hauser KW, Frias JL. Treatment of oral-facial clefts by state-affiliated craniofacial centers and cleft palate clinics. Birth Defects Res A Clin Mol Teratol. Sep 2003;67(9):643–646.

Appendix 2

List of Reportable Diseases and Conditions in Florida

Reportable Diseases/Conditions in Florida

Practitioner* List 11/24/08

Did you know that you are required by Florida statute to report certain diseases to your local county health department?**

*Reporting requirements for laboratories differ. For specific information on disease reporting, consult Rule 64D-3, *Florida Administrative Code (FAC)*.

! = Report immediately 24/7 by phone upon initial suspicion or laboratory test order

☎ = Report immediately 24/7 by phone

• = Report next business day

+ = Other reporting timeframe

- ! Any disease outbreak
- ! Any case, cluster of cases, or outbreak of a disease or condition found in the general community or any defined setting such as a hospital, school or other institution, not listed below that is of urgent public health significance. This includes those indicative of person to person spread, zoonotic spread, the presence of an environmental, food or waterborne source of exposure and those that result from a deliberate act of terrorism.
- Acquired Immune Deficiency Syndrome (AIDS)+
- Amebic encephalitis•
- Anaplasmosis•
- ! Anthrax
- Arsenic poisoning•
- ! Botulism (foodborne, wound, unspecified, other)
- Botulism (infant)•
- ! Brucellosis
- California serogroup virus (neuroinvasive and non-neuroinvasive disease)•
- Campylobacteriosis•
- Cancer (except non-melanoma skin cancer, and including benign and borderline intracranial and CNS tumors)+
- Carbon monoxide poisoning•
- Chancroid•
- Chlamydia•
- ! Cholera
- Ciguatera fish poisoning (Ciguatera)•
- Congenital anomalies•
- Conjunctivitis (in neonates ≤ 14 days old)•
- Creutzfeldt-Jakob disease (CJD)•
- Cryptosporidiosis•
- Cyclosporiasis•
- Dengue•
- ! Diphtheria
- Eastern equine encephalitis virus disease (neuroinvasive and non-neuroinvasive)•
- Ehrlichiosis•
- Encephalitis, other (non-arboviral)•
- ☎ Enteric disease due to:
  - *Escherichia coli*, O157:H7
  - *Escherichia coli*, other pathogenic *E. coli* including entero-toxigenic, invasive, pathogenic, hemorrhagic, aggregative strains and shiga toxin positive strains
- Giardiasis•
- ! Glanders
- Gonorrhea•
- Granuloma inguinale•
- ! *Haemophilus influenzae* (meningitis and invasive disease)
- Hansen's disease (Leprosy)•
- ☎ Hantavirus infection
- ☎ Hemolytic uremic syndrome
- ☎ Hepatitis A
- Hepatitis B, C, D, E, and G•
- Hepatitis B surface antigen (HBsAg) (positive in a pregnant woman or a child up to 24 months old)•
- Herpes simplex virus (HSV) (in infants up to 60 days old with disseminated infection with involvement of liver, encephalitis and infections limited to skin, eyes and mouth; anogenital in children ≤ 12 yrs)•
- Human Immunodeficiency Virus (HIV) infection (all, and including neonates born to an infected woman, exposed newborn)+
- Human papillomavirus (HPV) (associated laryngeal papillomas or recurrent respiratory papillomatosis in children ≤ 6 years of age; anogenital in children ≤ 12 yrs)•
- ! Influenza due to novel or pandemic strains
- ☎ Influenza-associated pediatric mortality (in persons aged < 18 yrs)
- Lead poisoning (blood lead level ≥ 10μg/dL); additional reporting requirements exist for hand held and/or on-site blood lead testing technology, see 64D-3 FAC•
- Legionellosis•
- Leptospirosis•
- ☎ Listeriosis
- Lyme disease•
- Lymphogranuloma venereum (LGV)•
- Malaria•
- ! Measles (Rubeola)
- ! Melioidosis
- Meningitis (bacterial, cryptococcal, mycotic)•
- ! Meningococcal disease (includes meningitis and meningococcemia)
- Mercury poisoning•
- Mumps•
- ☎ Neurotoxic shellfish poisoning
- ☎ Pertussis
- Pesticide-related illness and injury•
- ! Plague
- ! Poliomyelitis, paralytic and non-paralytic
- Psittacosis (Ornithosis)•
- Q Fever•
- ☎ Rabies (human, animal)
- ! Rabies (possible exposure)
- ! Ricin toxicity
- Rocky Mountain spotted fever•
- ! Rubella (including congenital)
- St. Louis encephalitis (SLE) virus disease (neuroinvasive and non-neuroinvasive)•
- Salmonellosis•
- Saxitoxin poisoning including paralytic shellfish poisoning (PSP)•
- ! Severe Acute Respiratory Syndrome-associated Coronavirus (SARS-CoV) disease
- Shigellosis•
- ! Smallpox
- *Staphylococcus aureus*, community associated mortality•
- ☎ *Staphylococcus aureus* (infection with intermediate or full resistance to vancomycin, VISA,VRSA)
- ☎ Staphylococcal enterotoxin B (disease due to)
- Streptococcal disease (invasive, Group A)•
- *Streptococcus pneumoniae* (invasive disease)•
- Syphilis•
- ☎ Syphilis (in pregnant women and neonates)
- Tetanus•
- Toxoplasmosis (acute)•
- Trichinellosis (Trichinosis)•
- Tuberculosis (TB)•
- ! Tularemia
- ☎ Typhoid fever
- ! Typhus fever (disease due to *Rickettsia prowazekii* infection)
- Typhus fever (disease due to *Rickettsia typhi, R. felis* infection)•
- ! Vaccinia disease
- Varicella (Chickenpox)•
- Varicella mortality•
- ! Venezuelan equine encephalitis virus disease (neuroinvasive and non-neuroinvasive)
- Vibriosis (Vibrio infections)•
- ! Viral hemorrhagic fevers (Ebola, Marburg, Lassa, Machupo)
- West Nile virus disease (neuroinvasive and non-neuroinvasive)•
- Western equine encephalitis virus disease (neuroinvasive and non-neuroinvasive)•
- ! Yellow fever

You are an invaluable part of Florida's disease surveillance system.

For more information, please call the epidemiology unit at your local county health department or the Bureau of Epidemiology, Florida Department of Health (FDOH): 850-245-4401 or visit http://www.doh.state.fl.us/disease_ctrl/epi/topics/surv.htm

FLORIDA DEPARTMENT OF HEALTH

****Section 381.0031(1,2),** Florida Statutes provides that "Any practitioner, licensed in Florida to practice medicine, osteopathic medicine, chiropractic, naturopathy, or veterinary medicine, who diagnoses or suspects the existence of a disease of public health significance shall immediately report the fact to the Department of Health." The FDOH county health departments serve as the Department's representative in this reporting requirement. Furthermore, this Section provides that "Periodically the Department shall issue a list of diseases determined by it to be of public health significance ... and shall furnish a copy of said list to the practitioners...."

Appendix 3

Birth Defects Reported to the NBDPN

NBDPN REPORTING CATEGORY	ICD-9-CM CODES INCLUDED IN CATEGORY
Anencephalus	740.0, 740.1
Spina bifida without anencephalus	741.00-741.03, 741.90-741.93 without either 740.0 or 740.1
Hydrocephalus without spina bifida	742.3 without any of 741.00-741.03, or 741.90-741.93
Encephalocele	742
Microcephalus	742.1
Anophthalmia/microphthalmia	743.00, 743.03, 743.06, 743.10-743.12
Congenital cataract	743.30-743.34
Aniridia	743.45
Anotia/microtia	744.01, 744.23
Common truncus	745
Transposition of great arteries	745.10-745.12, 745.19
Tetralogy of Fallot	745.2
Ventricular septal defect	745.4
Atrial septal defect	745.5
Endocardial cushion defect	745.60, 745.61, 745.69
Pulmonary valve atresia and stenosis	746.01, 746.02
Tricuspid valve atresia and stenosis	746.1
Ebstein's anomaly	746.2
Aortic valve stenosis	746.3
Hypoplastic left heart syndrome	746.7
Patent ductus arteriosus	747.0 (and birth weight >= 2500gm)
Coarctation of aorta	747.1
Cleft palate without cleft lip	749.00-749.04
Cleft lip with and without cleft palate	749.10-749.14, 749.20-749.25
Choanal atresia	748
Esophageal atresia/tracheoesophageal fistula	750.3
Rectal and large intestinal atresia/stenosis	751.2
Pyloric stenosis	750.5
Hirschsprung's disease (congenital megacolon)	751.3
Biliary atresia	751.61
Renal agenesis/hypoplasia	753
Bladder exstrophy	753.5
Obstructive genitourinary defect	753.20-753.23, 753.29, 753.6
Hypospadias and Epispadias	752.61-752.62
Reduction deformity: upper limbs	755.20-755.29
Reduction deformity: lower limbs	755.30-755.39
Gastroschisis/Omphalocele	756.79
Congenital hip dislocation	754.30-754.35
Diaphragmatic hernia	756.6
Trisomy 13	758.1
Down syndrome	758
Trisomy 18	758.2

Appendix 4

Florida population-based birth defects data: counts and prevalence, 2003–2007

PREVALENCE PER 10,000 LIVE BIRTHS

DEFECT	NON-HISPANIC WHITE	NON-HISPANIC BLACK OR AFRICAN	HISPANIC	ASIAN OR PACIFIC ISLANDER	AMERICAN INDIAN OR ALASKAN NATIVE	TOTAL**
Anencephalus	20	13	9	2	1	49
	0.38	0.54	0.28	0.68	3.48	0.43
Aniridia	4	4	1	0	0	9
	0.08	0.17	0.03	0.00	0.00	0.08
Anophthalmia/microphthalmia	56	24	18	3	0	102
	1.07	1.00	0.57	1.02	0.00	0.90
Anotia/microtia	34	7	25	2	0	69
	0.65	0.29	0.79	0.68	0.00	0.61
Aortic valve stenosis	118	27	36	1	0	187
	2.26	1.13	1.13	0.34	0.00	1.65
Atrioventricular spetal defect (endocardial cushion defect)	224	116	96	10	1	454
	4.29	4.86	3.02	3.40	3.48	4.02
Biliary atresia	51	41	29	2	1	128
	0.98	1.72	0.91	0.68	3.48	1.13
Bladder exstrophy	22	11	5	0	0	38
	0.42	0.46	0.16	0.00	0.00	0.34
Choanal atresia	88	32	37	2	0	162
	1.69	1.34	1.17	0.68	0.00	1.43
Cleft lip with & without cleft palate	525	119	248	23	1	925
	10.06	4.98	7.81	7.81	3.48	8.18
Cleft palate without cleft lip	337	97	146	18	1	606
	6.46	4.06	4.60	6.11	3.48	5.36
Coarctation of aorta	392	142	176	10	3	736
	7.51	5.95	5.54	3.40	10.43	6.51
Common truncus	56	18	25	1	0	100
	1.07	0.75	0.79	0.34	0.00	0.88
Congenital cataract	61	43	36	5	0	147
	1.17	1.80	1.13	1.70	0.00	1.30
Congenital hip dislocation	524	93	318	33	3	984
	10.04	3.89	10.02	11.21	10.43	8.71
Diaphragmatic hernia	155	71	91	5	0	330
	2.97	2.97	2.87	1.70	0.00	2.92
Down syndrome	703	300	434	32	4	1498
	13.47	12.56	13.67	10.87	13.91	13.25
Ebstein Anomaly	35	13	12	1	0	63
	0.67	0.54	0.38	0.34	0.00	0.56
Encephaolocele	35	29	31	2	2	101
	0.67	1.21	0.98	0.68	6.96	0.89
Epispadias	67	17	15	1	0	101
	1.28	0.71	0.47	0.34	0.00	0.89
Esophageal atresia/ tracheoesophageal fistula	121	42	77	3	1	246
	2.32	1.76	2.43	1.02	3.48	2.18
Gastroschisis	281	56	89	7	0	439
	5.38	2.34	2.80	2.38	0.00	3.88
Hirschsprung's disease (congenital megacolon)	129	76	44	5	2	260
	2.47	3.18	1.39	1.70	6.96	2.30
Hydrocephalus without Spina Bifida	309	270	210	20	2	822
	5.92	11.30	6.61	6.79	6.96	7.27
Hypoplastic left heart syndrome	159	96	59	3	0	321
	3.05	4.02	1.86	1.02	0.00	2.84
Hypospadias*	2243	693	751	68	2	3822
	83.88	56.98	46.13	44.83	13.57	66.06
Microcephalus	287	183	201	6	3	688
	5.50	7.66	6.33	2.04	10.43	6.09
Obstructive genitourinary defect	1727	545	1115	92	5	3551
	33.09	22.82	35.12	31.25	17.39	31.42
Pulmonary valve atresia & stenosis	531	363	269	24	6	1211
	10.17	15.20	8.47	8.15	20.87	10.72
Pyloric Stenosis	1925	362	728	22	5	3074
	36.88	15.16	22.93	7.47	17.39	27.20
Rectal and large intestinal atresia/stenosis	257	92	114	17	1	487
	4.92	3.85	3.59	5.77	3.48	4.31
Reduction deformity: lower limbs	72	30	42	4	0	151
	1.38	1.26	1.32	1.36	0.00	1.34
Reduction deformity: upper limbs	101	45	47	3	0	198
	1.93	1.88	1.48	1.02	0.00	1.75
Renal agenesis/hypoplasia	201	81	109	7	0	408
	3.85	3.39	3.43	2.38	0.00	3.61
Spina bifida without anencephalus	170	65	91	2	2	332
	3.26	2.72	2.87	0.68	6.96	2.94
Teralogy of Fallot	302	135	136	12	2	593
	5.79	5.65	4.28	4.08	6.96	5.25
Transposition of great arteries	250	111	131	9	0	505
	4.79	4.65	4.13	3.06	0.00	4.47
Tricuspid valve atresia & stenosis	70	27	39	2	1	141
	1.34	1.13	1.23	0.68	3.48	1.25
Trisomy 13 (Patau syndrome)	46	25	21	1	0	94
	0.88	1.05	0.66	0.34	0.00	0.83
Trisomy 18 (Edwards syndrome)	71	61	42	5	0	183
	1.36	2.55	1.32	1.70	0.00	1.62
Ventricular septal defect	2787	1167	1798	104	12	5935
	53.39	48.86	56.63	35.33	41.74	52.52
Total Live Births	521985	238847	317473	29439	2875	1130141
Total Male Live Births	267417	121625	162815	15169	1474	578551

*Hypospadias: pervalence per 10,000 male live births

**Total includes other and unknown race

Appendix 4

Florida population-based birth defects data: counts and prevalence by maternal age, 2003–2007

PREVALENCE PER 10,000 LIVE BIRTHS

DEFECT	AGE		
	<35	35 and >	Total**
Down syndrome (Trisomy 21)	828	670	1498
	8.58	40.49	13.25
Trisomy 13 (Patau Syndrome)	75	19	94
	0.78	1.15	0.83
Trisomy 18 (Edwards Syndrome)	98	85	183
	1.02	5.14	1.62
Total Live Births	964579	165459	1130141

**Total includes unknown age

1. Gastroschisis (2002–2007): distinguished from other adominal wall defects using 54.71 procedure code
2. Ventricular septal defect (2002–2007): probably cases are included in these counts
3. Only live births are considered; stillbirths and terminations are not reported.

Appendix 5

Helpful Links

THE FLORIDA BIRTH DEFECTS REGISTRY: www.fbdr.org

Provides statewide and county specific information on birth defects, including frequencies and rates

THE FLORIDA FOLIC ACID COALITION: www.folicacidnow.net

The mission of the FFAC is to decrease the incidence of folic acid preventable birth defects and to reduce chronic disease risk in Floridians

CHILDREN'S MEDICAL SERVICES: www.cms-kids.com

Serves Florida children with special needs and oversees programs such as the Florida Early Intervention and Early Steps programs

FLORIDA FIGHTS FETAL ALCOHOL SPECTRUM DISORDERS: www.fasd-fl.org

An organization that brings state representatives, executives, community leaders and members together to engage and educate Floridians about the dangers of alcohol consumption during pregnancy

MARCH OF DIMES: www.marchofdimes.com/florida

An organization developed to help moms have full-term pregnancies and to research problems that threaten the health of babies

NATIONAL BIRTH DEFECTS PREVENTION NETWORK: www.nbdpn.org

A network of state birth defect programs that address the issues of birth defects surveillance, research, and prevention in the United States

CDC NATIONAL CENTER ON BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES (NCBDDD): www.cdc.gov/ncbddd/bd/default.htm

Contains information on specific birth defects nationwide, including risk factors and prevalence rates

NATIONAL HEALTHY MOTHERS, HEALTHY BABIES COALITION: www.hmhb.org

Coalition working to improve the health and safety of mothers, babies, and families through education

INTERNATIONAL CLEARINGHOUSE FOR BIRTH DEFECTS SURVEILLANCE AND RESEARCH: www.icbdsr.org

An organization aimed to bring together birth defect programs from around the world to conduct worldwide surveillance and research for birth defect prevention

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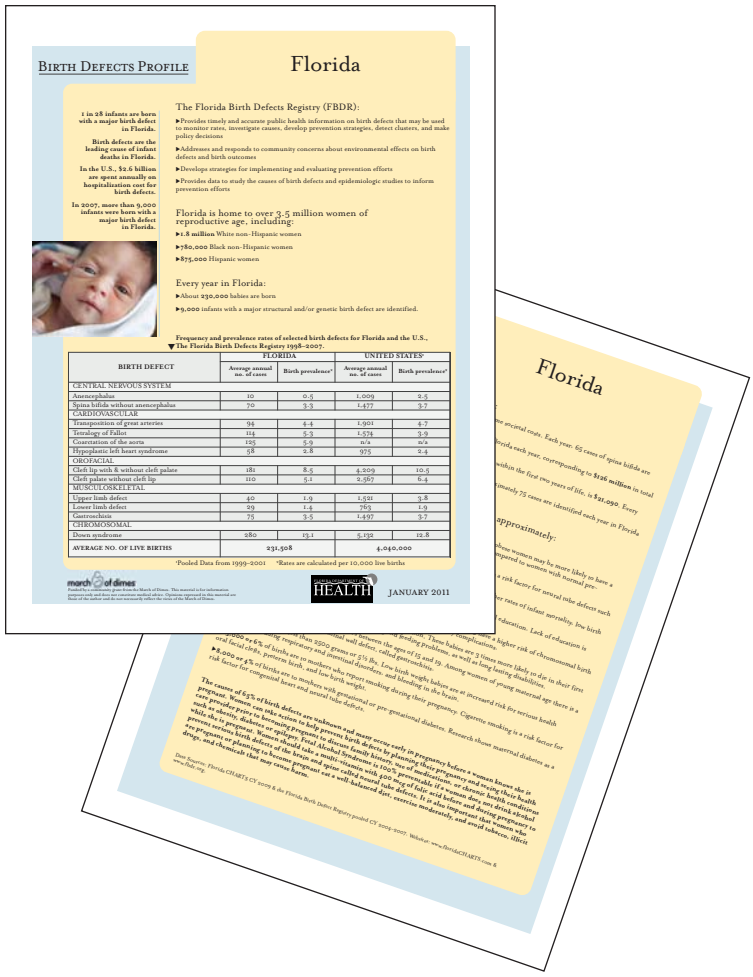
Florida Birth Defect Registry Resources

The following information sheets are not copyrighted and are avaliable for distribution and inclusion in publications: the "State of Florida Birth Defects Profile" and the"Florida Birth Defects Registry Importance." Additional county birth defects profiles can be found at www.fbdr.org.



BIRTH DEFECTS PROFILE

Florida

1 in 28 infants are born with a major birth defect in Florida.

Birth defects are the leading cause of infant deaths in Florida.

In the U.S., $2.6 billion are spent annually on hospitalization cost for birth defects.

In 2007, more than 9,000 infants were born with a major birth defect in Florida.

The Florida Birth Defects Registry (FBDR):

- Provides timely and accurate public health information on birth defects that may be used to monitor rates, investigate causes, develop prevention strategies, detect clusters, and make policy decisions
- Addresses and responds to community concerns about environmental effects on birth defects and birth outcomes
- Develops strategies for implementing and evaluating prevention efforts
- Provides data to study the causes of birth defects and epidemiologic studies to inform prevention efforts

Florida is home to over 3.5 million women of reproductive age, including:

- **1.8 million** White non-Hispanic women
- **780,000** Black non-Hispanic women
- **875,000** Hispanic women

Every year in Florida:

- About **230,000** babies are born
- **9,000** infants with a major structural and/or genetic birth defect are identified.

Frequency and prevalence rates of selected birth defects for Florida and the U.S., ▼The Florida Birth Defects Registry 1998–2007.

BIRTH DEFECT	FLORIDA		UNITED STATES*	
	Average annual no. of cases	Birth prevalence*	Average annual no. of cases	Birth prevalence*
CENTRAL NERVOUS SYSTEM				
Anencephalus	10	0.5	1,009	2.5
Spina bifida without anencephalus	70	3.3	1,477	3.7
CARDIOVASCULAR				
Transposition of great arteries	94	4.4	1,901	4.7
Tetralogy of Fallot	114	5.3	1,574	3.9
Coarctation of the aorta	125	5.9	n/a	n/a
Hypoplastic left heart syndrome	58	2.8	975	2.4
ORO-FACIAL				
Cleft lip with & without cleft palate	181	8.5	4,209	10.5
Cleft palate without cleft lip	110	5.1	2,567	6.4
MUSCULOSKELETAL				
Upper limb defect	40	1.9	1,521	3.8
Lower limb defect	29	1.4	763	1.9
Gastroschisis	75	3.5	1,497	3.7
CHROMOSOMAL				
Down syndrome	280	13.1	5,132	12.8
AVERAGE NO. OF LIVE BIRTHS	**231,508**		**4,040,000**	

*Pooled Data from 1999-2001 *Rates are calculated per 10,000 live births

march of dimes — Funded by a cooperative grant from the March of Dimes. This material is for information purposes only and does not constitute medical advice. Opinions expressed in this material are those of the author and do not necessarily reflect the views of the March of Dimes.

FLORIDA DEPARTMENT OF HEALTH — JANUARY 2011

IMPORTANCE

The Florida Birth Defects Registry

Public health importance

- In 2007, more than 9,000 infants were born with major structural or genetic birth defects in Florida. In the U.S., one in 33 babies is born with a birth defect affecting about 120,000 babies each year.
- Birth defects are the leading cause of death in children less than 1 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.
- During 2004, hospital costs in the U.S. for birth defects totaled $2.6 billion and accounted for more than 139,000 hospitalizations.
- Causes of most birth defects are unknown.
- Floridians are very concerned about the possible association between birth defects and environmental contamination.

Birth defects monitoring systems are vital

- For tracking and detecting trends in birth defects.
- For identifying when and where birth defects can possibly be prevented.
- For providing the basis for studies on the genetic and environmental causes of birth defects.
- For planning and evaluating the impact of efforts to prevent birth defects.
- For helping Florida's families whose infants and children need appropriate medical, educational and social services.

The good news

- State funding for the birth defects registry is critical for describing the public health impact of birth defects in Florida. Without this data, Florida would be unable to competitively compete for additional funds to enhance surveillance, intervention and prevention programs. Since 1999, state funding has allowed the department to successfully compete and receive more than $5,295,000 in additional funding to support enhanced efforts.
- Folic acid prevents most neural tube defects (NTDs), serious birth defects of the brain and spine, when taken by women prior to and early in pregnancy. The number of infants born with NTDs in Florida has dropped since education, fortification and supplementation activities began, saving more than $28 million in health care costs in Florida.
- Fetal Alcohol Spectrum Disorders (FASDs) are 100% preventable. Annual cost estimates for FASDs in Florida, including special education and juvenile justice, are $493,567,966.
- Genetic counseling provides parents with information about their risks based on family history, age, ethnic or racial background.
- The Florida Folic Acid Coalition, a public-private partnership, is working to decrease the incidence of folic acid preventable birth defects. Partners have developed and disseminated nationally recognized health promotion and education materials to women and their health care providers (www.folicacidnow.net).

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FLORIDA DEPARTMENT OF HEALTH — JANUARY 2011

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▶Addresses and responds to community concerns about environmental effects on birth defects and birth outcomes

▶Develops strategies for implementing and evaluating prevention efforts

▶Provides data to study the causes of birth defects and epidemiologic studies to inform prevention efforts

In 2009, Florida was home to over 3.5 million women of reproductive age, including:

▶**1.8 million** White non-Hispanic women

▶**780,000** Black non-Hispanic women

▶**875,000** Hispanic women

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▶About **230,000** babies are born

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CENTRAL NERVOUS SYSTEM				
Anencephalus	10	0.5	1,009	2.5
Spina bifida without anencephalus	70	3.3	1,477	3.7
CARDIOVASCULAR				
Transposition of great arteries	94	4.4	1,901	4.7
Tetralogy of Fallot	114	5.3	1,574	3.9
Coarctation of the aorta	125	5.9	n/a	n/a
Hypoplastic left heart syndrome	59	2.8	975	2.4
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Cleft lip with & without cleft palate	181	8.5	4,209	10.5
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FLORIDA DEPARTMENT OF HEALTH

JANUARY 2011

Birth Defects Profile

Florida

Economic impact of birth defects for Florida:

▶Each case of spina bifida is estimated to cost **$636,000** in lifetime societal costs. Each year, 70 cases of spina bifida are identified in Florida with an estimated cost of **$44.5 million**.

▶Approximately 280 children are born with Down syndrome in Florida each year, corresponding to **$126 million** in total lifetime medical, non-medical, and indirect costs.

▶The mean cost of hospitalizations for a child with an orofacial cleft, within the first two years of life, is **$21,090**. Every year, 290 babies are born with an orofacial cleft in Florida.

▶Gastroschisis repair costs (in 1992) was estimated at **$108,000**; approximately 75 cases are identified each year in Florida corresponding to **$8.1 million**.

Of the 230,000 babies born EACH YEAR in Florida approximately:[1]

▶**100,000 or 43%** of births are covered by Medicaid.

▶**92,500 or 40%** are born to an overweight or obese mother. Overweight and obese women may be more likely to have a baby born with a congenital heart defect, neural tube defect, or limb defects, compared to women with normal pre-pregnancy weight.

▶**66,000 or 29%** are born to a mother of Hispanic ethnicity. Hispanic ethnicity is a risk factor for neural tube defects such as spina bifida.

▶**48,000 or 21%** are born to a Black mother. Infants born to black women have higher rates of infant mortality, low birth weight, and specific congenital heart defects, such as tetralogy of Fallot.

▶**37,700 or 16%** of them are born to women over 18 years of age without a high school education. Lack of education is associated with an increased risk for low-birth weight babies.

▶**33,000 or 14%** are born to women 35 years or older. Women over the age of 35 have a higher risk of chromosomal birth defects, such as Down syndrome, and may be more likely to have pregnancy complications.

▶**25,500 or 11%** are born pre-term or less than 37 weeks gestation. These babies are 3 times more likely to die in their first year of life, and are at an increased risk for breathing and feeding problems, as well as long lasting disabilities.

▶**25,000 or 11%** are born to teenage mothers between the ages of 15 and 19. Among women of young maternal age there is a 10 times increased risk for an abdominal wall defect, called gastroschisis.

▶**20,000 or 9%** weigh less than 2500 grams or 5½ lbs. Low birth weight babies are at increased risk for serious health problems, including respiratory and intestinal disorders, and bleeding in the brain.

▶**21,000 or 9%** of births are to mothers who report smoking during their pregnancy. Cigarette smoking is a risk factor for oral facial clefts, preterm birth, and low birth weight.

▶**9,100 or 4%** of births are to mothers with gestational or pre-gestational diabetes.[2] Research shows maternal diabetes as a risk factor for congenital heart and neural tube defects.

The causes of 65% of birth defects are unknown and many occur early in pregnancy before a woman knows she is pregnant. Women can take action to help prevent birth defects by planning their pregnancy and seeing their health care provider prior to becoming pregnant to discuss family history, use of medications, or chronic health conditions such as obesity, diabetes or epilepsy. Fetal Alcohol Syndrome is 100% preventable if a woman does not drink alcohol while she is pregnant. Women should take a multi-vitamin with 400 mcg of folic acid before and during pregnancy to prevent serious birth defects of the brain and spine called neural tube defects. It is also important that women who are pregnant or planning to become pregnant eat a well-balanced diet, exercise moderately, and avoid tobacco, illicit drugs, and chemicals that may cause harm.

Data Sources:
1. Florida CHARTS (www.floridaCHARTS.com).
2. The Florida Birth Defect Registry pooled CY March 2004–December 2007 (www.fbdr.org).

IMPORTANCE

The Florida Birth Defects Registry

Public Health Importance

▶In 2007, more than 9,000 infants were born with major structural or genetic birth defects in Florida. In the U.S., one in 33 babies is born with a birth defect affecting about 120,000 babies each year.

▶Birth defects are the leading cause of death in children less than 1 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.

▶During 2004, hospital costs in the U.S. for birth defects totaled $2.6 billion and accounted for more than 139,000 hospitalizations.

▶Causes of most birth defects are unknown.

▶Floridians are very concerned about the possible association between birth defects and environmental contamination.

Birth Defects Monitoring Systems are Vital

▶For tracking and detecting trends in birth defects.

▶For identifying when and where birth defects can possibly be prevented.

▶For providing the basis for studies on the genetic and environmental causes of birth defects.

▶For planning and evaluating the impact of efforts to prevent birth defects.

▶For helping Florida's families whose infants and children need appropriate medical, educational and social services.

The Good News

▶State funding for the birth defects registry is critical for describing the public health impact of birth defects in Florida. Without this data, Florida would be unable to competitively compete for additional funds to enhance surveillance, intervention and prevention programs. Since 1999, state funding has allowed the department to successfully compete and receive more than $5,295,000 in additional funding to support enhanced efforts.

▶Folic acid prevents most neural tube defects (NTDs), serious birth defects of the brain and spine, when taken by women prior to and early in pregnancy. The number of infants born with NTDs in Florida has dropped since education, fortification and supplementation activities began, saving more than $28 million in health care costs in Florida.

▶Fetal Alcohol Spectrum Disorders (FASDs) are 100% preventable. Annual cost estimates for FASDs in Florida are unknown. However, in 2002, the Substance Abuse and Mental Health Services Administration estimated costs, excluding lost productivity, at $1.6 million per person.

▶Genetic counseling provides parents with information about their risks based on family history, age, ethnic or racial background.

▶The Florida Folic Acid Coalition, a public-private partnership, is working to decrease the incidence of folic acid preventable birth defects. Partners have developed and disseminated nationally recognized health promotion and education materials to women and their health care providers (www.folicacidnow.net).

march of dimes

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FLORIDA DEPARTMENT OF HEALTH

JANUARY 2011

Early Steps Training Expenditures

February 15, 2010 thru Decebmer 30, 2010

LES:

Amount	Explanation of Training Activity or Training Materials Purchased
$0.00	**TOTAL**