



Health Quality Subcommittee

Wednesday, January 15, 2014
2:30 PM – 4:30 PM
306 HOB

Will Weatherford
Speaker

Kenneth L. "Ken" Roberson
Chair

Committee Meeting Notice

HOUSE OF REPRESENTATIVES

Health Quality Subcommittee

Start Date and Time: Wednesday, January 15, 2014 02:30 pm
End Date and Time: Wednesday, January 15, 2014 04:30 pm
Location: 306 HOB
Duration: 2.00 hrs

Overview of the Department of Health's Newborn Screening Program

NOTICE FINALIZED on 01/08/2014 15:05 by Iseminger.Bobbye

Children's Medical Services Newborn Screening Program

House Health Quality Subcommittee

January 15, 2014



Dr. Celeste Philip, MD, MPH

Deputy Secretary for Health

Deputy State Health Officer for Children's Medical
Services

Objectives

- Newborn Screening Program Overview
- Disorders Included in the Florida Newborn Screening Program
- The Impact of Newborn Screening on the Lives of Florida's Youngest Citizens



Newborn Screening Program



- Florida began newborn screening in 1965
- Highly successful public health program
 - No eligibility criteria
 - Mandatory screening but families can opt out
- Goal - to screen newborns for selected disorders and provide treatment before permanent developmental and physical damage or death occur.

Newborn Screening Process



- Hospitals collect the bloodspot specimen and perform the hearing screening and pulse oximetry screening before the newborn is discharged
- Specimens are sent to the Newborn Screening Laboratory in Jacksonville for testing

Newborn Screening Process



- Abnormal results are managed by the Follow-up Program in Tallahassee
- Newborns with abnormal results are referred to specialists for confirmatory testing, diagnosis and treatment

37 Disorders Tested in Florida

- 1965 Phenylketonuria (PKU)
- 1978 Galactosemia,
Congenital Hypothyroidism
- 1989 Hemoglobin Disorders (3)
- 1995 Congenital Adrenal Hyperplasia
- 2000 Hearing Loss
- 2005 Biotinidase Deficiency
- 2006 Additional Metabolic Disorders (25)
- 2007 Cystic Fibrosis
- 2012 Severe Combined Immunodeficiency (SCID)
- 2013 Critical Congenital Heart Disease (CCHD)



Benefits of Early Detection



Initiate treatment or institute critical precautions before a health care crisis to prevent permanent intellectual disability and/or death

Adding Disorders to the Newborn Screening Panel



1. United States Department of Health and Human Services (HHS), Secretary's Advisory Committee on Heritable Disorders for Newborns and Children (SACHDNC) recommends a disorder
2. HHS Secretary adds the disorder to the Recommended Uniform Screening Panel (RUSP)

Adding Disorders to the Newborn Screening Panel



3. Florida Genetics and Newborn Screening Advisory Council recommends the disorder to the Department of Health
4. The Florida Department of Health adds the disorder to the panel of newborn screening disorders

How Does Florida Compare to Other States



- Florida screens for **ALL** disorders recommended by the Department of Health and Human Services Secretary's Advisory Committee on Heritable Disorders for Newborns and Children
- Some states have not yet implemented SCID or CCHD

Funding



How is Newborn Screening Paid for in Florida?

- Newborn Screening services in Florida are jointly funded through billing Medicaid and private insurance for the newborn screening tests
- \$15.00 fee paid by birthing facilities for each live birth.

Funding



- 2 Federal grants for hearing program.
\$263,680 and \$147,445 = \$411,125
- \$155,992 recurring and \$50,000 nonrecurring
for Critical Congenital Heart Disease (CCHD)

Impact of Newborn Screening



Why does every state and territory in the United States and most countries have a newborn screening program?

Newborn Screening in 2012

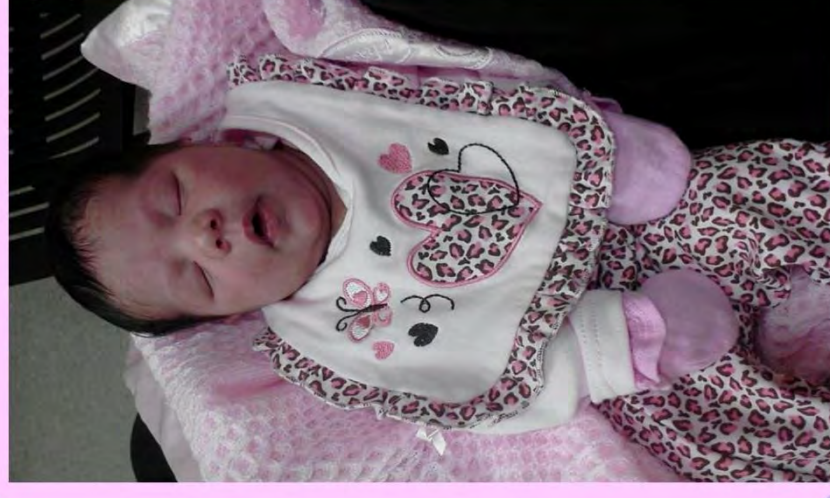
7	Phenylketonuria
4	Galactosemia,
68	Congenital Hypothyroidism
195	Hemoglobin Disorders (Sickle Cell)
14	Congenital Adrenal Hyperplasia
242	Hearing Loss
3	Biotinidase Deficiency
34	Additional Metabolic Disorders
41	Cystic Fibrosis
2	Severe Combined Immunodeficiency



Baby Aaliyah

- Diagnosed with SCID at 6 days old
- Received a life saving stem cell transplant
- Currently functioning as a normal baby

Featured online by Immune Deficiency Foundation and the Herald Tribune 2012



Mayer

- Screening test was abnormal; Began PKU formula at six days of age
- Diagnosed with PKU at 9 days of age
- Currently doing well and is managed through a special diet and formula



Featured on DOH's Online Newsroom

Jocelyn

- Diagnosed at two months of age with Hearing Loss
- Received hearing aids at four months of age
- Received speech therapy and learned American Sign Language

Letter from parent posted at www.floridanewbornscreening.com



Presentation Summary



- The Newborn Screening Program in Florida will celebrate 50 years of newborn screening in 2015
- Florida is testing for **ALL** disorders recommended by the national advisory committee and the Florida Genetics and Newborn Screening Advisory Council
- Children’s lives are saved every day because of newborn screening

Questions

