

# Newborn Screening Strategy Summit and Awareness Campaign

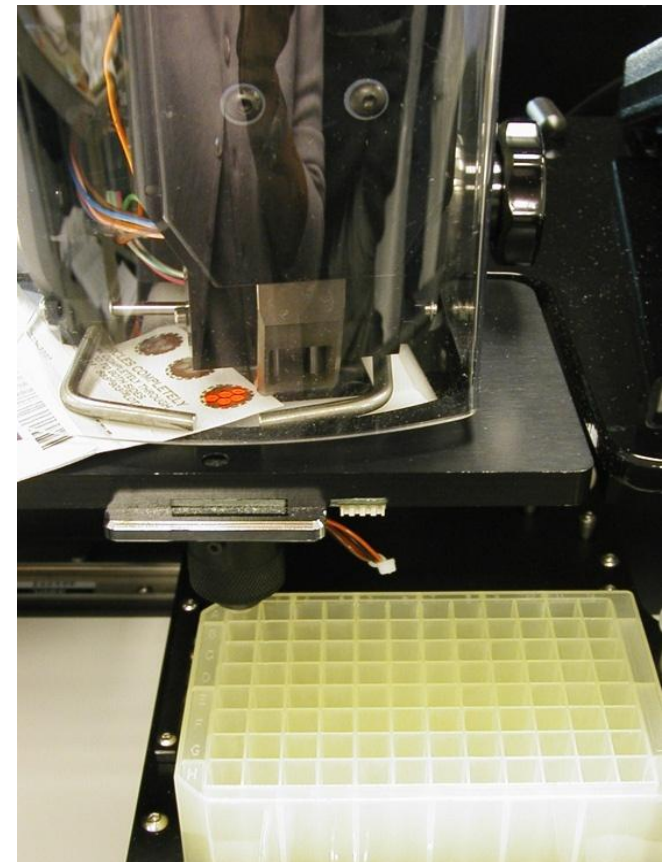
**FILL ALL 4 CIRCLES COMPLETELY**  
BLOOD MUST BE SUBMITTED COMPLETELY THROUGH  
DO NOT APPLY BLOOD TO BOTTLE  
DO NOT USE AFTER 15:00 - 8:00 EST LOT W-041

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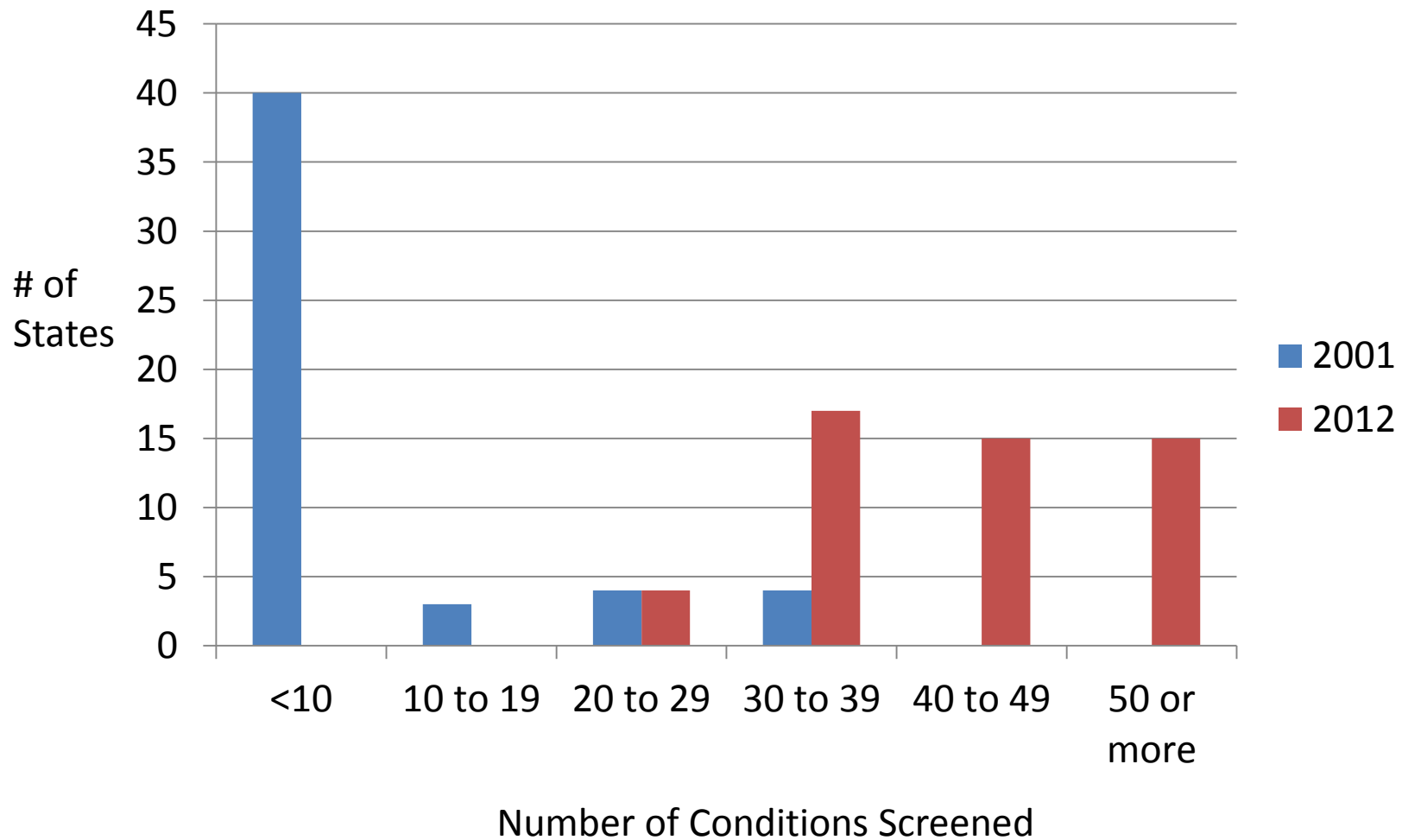
BIRTH NAME LAST FIRST  
ADDRESS STREET CITY STATE COUNTY  
PARENT'S PHONE NO HOSPITAL OR OTHER FACILITY ID  
PEDIATRIC MEDICAL CLINIC NUMBER  
PEDIATRIC CLINIC  
CITY STATE ZIP  
BILING NUMBER PROGRAM NUMBER

SEX  M  F RACE  
MOTHER'S NAME FIRST MIDDLE  
MOTHER'S AGE YRS  
FIRST FEEDING  BREAST  MIXED  BOTTLE  
BIRTH WEIGHT CMS  
PRESENT WEIGHT CMS  
TRANSFUSION  YES  NO  
COUNTRY OF BIRTH  USA  OTHER  
DATE OF BIRTH MONTH DAY YEAR  
TIME OF BIRTH AM PM

1. PRINT "PRE" WHEN T-4 HAS CP, GALT 1. T-4 ONLY 1. T-4R ONLY 1. GALT ONLY  
1. T-4R ONLY 1. T-4R ONLY 1. T-4R ONLY 1. T-4R ONLY



# Newborn screening is rapidly changing



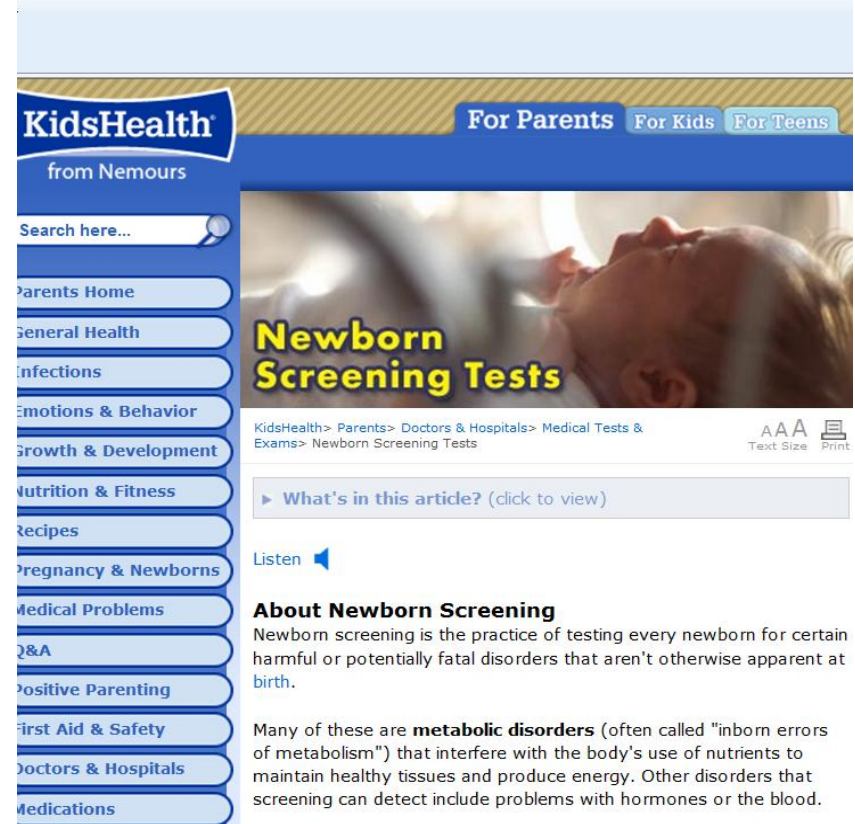
# But....

- We in this room are intimately aware of these changes, the complexities inherent making these changes happen in a rational way across all states, and magnitude of effort involved in implementing a comprehensive program of screening, follow-up, and treatment
- For us, this is our world
- For everyone else....



# Public Awareness

- ACOG, AAP, IOM, ACMG, APHL, MCHB, CDC all recommend educating expectant parents about NBS
- But implementing these recommendations is highly variable
- Research consistently shows that many parents are generally unaware of NBS
- Especially true for minority and low-income parents
- If aware, limited to “the heel stick” or “the PKU test”
- Lots of info on the web, but you have to want to look for it



The screenshot shows the KidsHealth website interface. At the top, the logo reads "KidsHealth from Nemours". Navigation tabs for "For Parents", "For Kids", and "For Teens" are visible. A search bar is located below the logo. A vertical sidebar on the left contains a list of categories: Parents Home, General Health, Infections, Emotions & Behavior, Growth & Development, Nutrition & Fitness, Recipes, Pregnancy & Newborns, Medical Problems, Q&A, Positive Parenting, First Aid & Safety, Doctors & Hospitals, and Medications. The main content area features a large image of a newborn baby with the title "Newborn Screening Tests" in yellow text. Below the image, the breadcrumb trail reads "KidsHealth > Parents > Doctors & Hospitals > Medical Tests & Exams > Newborn Screening Tests". There are links for "Text Size" and "Print". A section titled "What's in this article? (click to view)" is present. Below that, a "Listen" button with a speaker icon is shown. The article title "About Newborn Screening" is followed by a paragraph: "Newborn screening is the practice of testing every newborn for certain harmful or potentially fatal disorders that aren't otherwise apparent at birth." A second paragraph explains: "Many of these are **metabolic disorders** (often called 'inborn errors of metabolism') that interfere with the body's use of nutrients to maintain healthy tissues and produce energy. Other disorders that screening can detect include problems with hormones or the blood."

# North Carolina Brochure

## What is cystic fibrosis?

Cystic Fibrosis (CF) is a condition that affects breathing and digestion. People with CF have very thick mucus, which can clog the lungs and digestive system leading to a severe cough, life-threatening lung infections, and poor weight gain and growth. There are a variety of treatments for CF that involve daily breathing therapy and medication. Early diagnosis and treatment can improve growth, lung function, and add years to life.

## What are amino acid disorders, organic acid disorders, and fatty acid oxidation disorders?

Each of these disorders affects the body's ability to produce energy from food. These conditions cause the buildup of toxins in the body. Two of the most common conditions in this group are phenylketonuria (PKU) and medium chain acyl-CoA dehydrogenase deficiency (MCADD).

## What is phenylketonuria (PKU)?

PKU is a disorder that affects the body's ability to break down phenylalanine, which is part of the protein found in foods. The build up of phenylalanine in the blood can affect brain development and cause severe mental retardation and behavioral problems. Treatment places the baby on a special infant formula and life-long diet.

## What is medium chain acyl-CoA dehydrogenase deficiency (MCADD)?

MCADD is a disorder that affects the body's ability to make energy from stored fats. Babies born with this condition seem normal at birth, but they can suddenly have seizures and go into a coma if they have not eaten for a long period. Without emergency treatment they may die or be left with developmental problems. Treatment includes avoiding long periods without eating, especially during times of illness.



*If you have any concerns about the results of the screening tests, please contact your baby's doctor.*

*Newborn screening is not a diagnostic test. Although a normal result is very reassuring, it does not guarantee that a baby does not have one of these disorders. If a baby develops symptoms of one of these disorders, the baby should be further examined, even if the newborn screen was normal.*



State of North Carolina  
Department of Health and Human Services  
Division of Public Health  
Jeffrey P. Engel, M.D., State Health Director  
Women's and Children's Health Section

Children with Special Health Care Needs Help Line  
1-800-737-3028

[www.ncdhhs.gov](http://www.ncdhhs.gov)  
<http://dph.state.nc.us>

N.C. DHHS is an equal opportunity employer and provider.  
04/09



A TEST TO SAVE

YOUR  
BABY'S LIFE



Newborn Sc

## Your Questions Answered

### How will this test help protect my baby?

Most babies are born healthy and normal, but some health problems are not always spotted at birth. Newborn screening is the best way to help identify and prevent serious health problems before your baby becomes sick. This is why North Carolina performs a simple blood test to check newborns for over 30 conditions. Many of these illnesses are life-threatening and can cause serious long-term problems if they are not treated early. The earlier a problem is found and treated, the better chance your baby will have for a healthy start in life!

### How and where is my baby tested?

Before leaving the hospital, your baby's heel will be pricked and a few drops of blood will be collected. The blood will be sent to the State Laboratory of Public Health in Raleigh for testing. North Carolina is a nationally recognized leader in newborn screening.

### What if my baby needs a retest?

After you get home from the hospital, your baby's doctor may ask you to bring your baby in for another newborn screen or other types of testing. If more testing is requested it is very important that you respond as soon as possible. Some of these conditions can cause life-threatening problems in just a few days.

### What is included in the test?

The conditions your baby will be checked for are all treatable and they include:

- Congenital primary hypothyroidism
- Galactosemia
- Congenital adrenal hyperplasia (CAH)
- Sickle cell disease
- Biotinidase deficiency
- Cystic Fibrosis
- Amino acid disorders (including phenylketonuria, PKU)
- Organic acid disorders
- Fatty acid oxidation disorders (including medium chain acyl-CoA dehydrogenase deficiency, MCADD)

### What if we have no family history of these disorders?

Most of these health problems are inherited – passed down in families. However, a new baby can be the first person in the family to have the illness. Parents who do not have a family history of these conditions, or have healthy children already, can still have a baby with one of these illnesses.

## Explaining the Disorders

For each of these disorders, early diagnosis and treatment can prevent or reduce serious medical problems and may even save your baby's life.

### What is primary hypothyroidism?

The thyroid gland, which is located in the neck, makes a hormone that is important for normal growth, development, and learning. Primary hypothyroidism occurs when a baby's thyroid gland does not make enough thyroid hormone. Treatment is by hormone replacement.

### What is galactosemia?

Galactosemia is a condition that does not allow the body to use a sugar called galactose that is found in milk. A baby with galactosemia can become very ill after just a few days of drinking breast milk or formula that contains this sugar. The early symptoms may include vomiting, liver damage, or failure to thrive. Treatment involves changing to a galactose-free (soy-based) formula.

### What is congenital adrenal hyperplasia (CAH)?

CAH is a group of disorders that affect the amount of hormones produced by the adrenal glands, which are located above the kidneys. These hormones are necessary for life and play an important role in sexual development. Symptoms of CAH can be life-threatening and may include weakness, dehydration, or even shock. If your baby has CAH, the baby's body cannot make these hormones. Treatment is by hormone replacement.

### What is sickle cell disease?

Sickle cell disease is a disorder of red blood cells. Sickle cell disease affects the part of the red blood cell that carries oxygen throughout the body. People with sickle cell disease can have serious health problems that can lead to anemia (low red blood cell count), severe pain, life-threatening infections, strokes, and many hospitalizations. Penicillin helps prevent and treat symptoms.

### What is biotinidase deficiency?

Biotinidase deficiency is a condition that affects the body's ability to recycle biotin, a common vitamin found in many foods. Biotinidase deficiency can cause seizures, mental retardation, skin rash, hair and hearing loss, and even death. Treatment consists of daily biotin.

- Most states have a brochure
- Generally not read
- Suboptimal readability
- Often gets lost in “the packet”



# Public Acceptance

- Screening is mandatory in most states
- Very few parents object
- Despite lack of awareness, studies show high levels of public acceptance
- As information becomes more uncertain with less clear benefit, acceptance is reduced



# Do We Have a Problem?

- Most parents say they would like to know more about NBS and sooner
- Distribution of materials depends on provider and setting
- Role of provider in calling attention to NBS is probably important
- Controversies over dried blood spot storage after NBS have the potential to spill over and affect the NBS program

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### Court orders new constraints on newborn screening program

Article by: TONY KENNEDY, Star Tribune | Updated: November 16, 2011 - 2:40 PM

Blood screening program can continue, but privacy advocates deserve to be heard, state Supreme Court rules.



# Goals for NBS Awareness Campaign Strategy Summit

- Consider strategies for improving parent awareness and continued support for NBS
- Consider strategies for expanding active provider involvement in public awareness
- In all cases, think about focus, audience, messages
- Provide input for CDC and APHL to consider in planning the 2013 50<sup>th</sup> anniversary campaign
- Think beyond the campaign to other awareness goals and strategies



# Developing a Plan

- Partners within and outside of NBS were convened to plan a campaign to inform and educate the public about newborn screening, maintaining and increasing acceptance of newborn screening among parents.

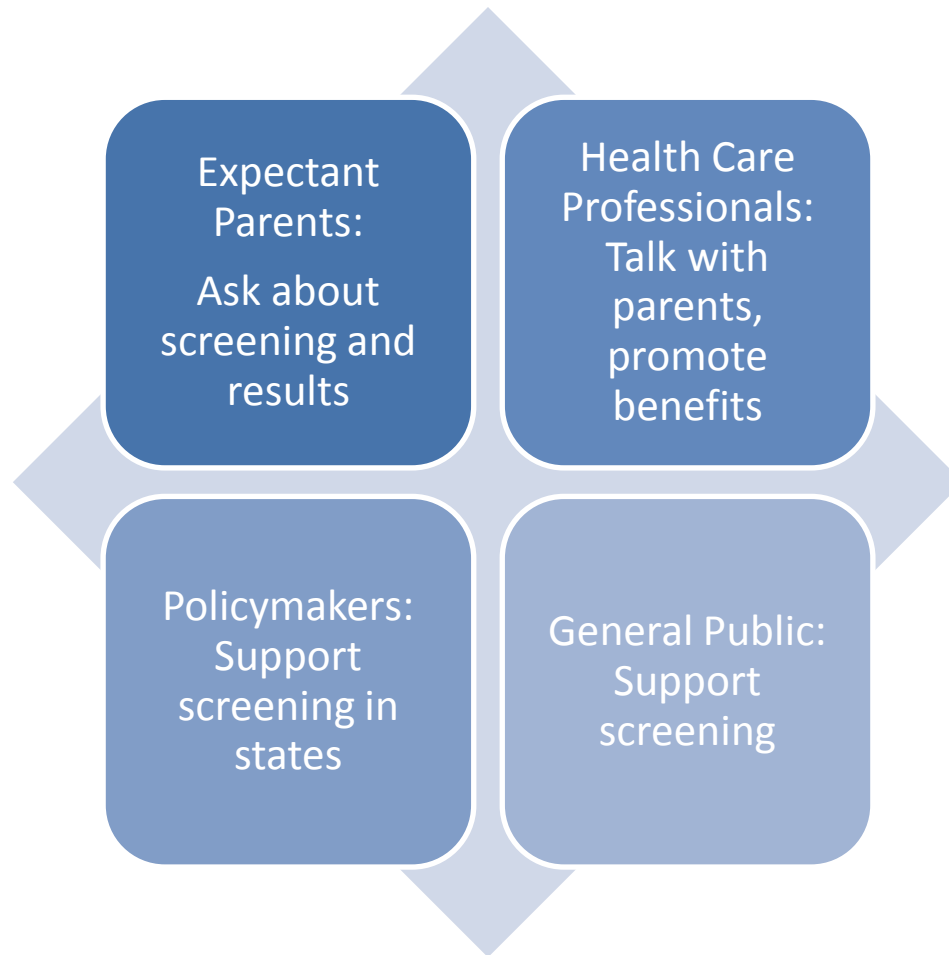
# The Goal

The campaign to inform and educate the public about newborn screening in order to maintain and/or increase the understanding, acceptance, and follow-up about of newborn screening among parents.

# Potential Audiences



# Calls to Action for Each Audience



# Prioritizing Parents: A Look at Their Journey

I have not heard of newborn screening, nor do I know what it is about.

• *Awareness*

I have heard about it and may ask my doctor or go check it out next time I go online.

• *Education, affirmation*

I know my baby will be screened at the hospital and believe that is a good thing.

• *Reduce barriers, provide tools*

Knowing my baby is screened is important to me. I am going to check with my OB about what my baby will be screened for and ask at the hospital to make sure the tests were done.”

• *Support*

I know it is important to ask my baby’s pediatrician to review the results with me and if the test reveals anything I need to follow up on, I will get a referral for further testing.

• *Reinforce*

# Parents

- Value of the program
  - Newborn screening saves lives by detecting problems early and getting babies to appropriate care.
- Value to parents
  - Your child is going to get a health check-up at birth. Make sure you ask the doctor for the results.
  - You ask about your baby's height and weight. Do you know your baby's NBS results?

# Parents

- Early detection
  - Your child's newborn screening – a simple heel prick test – helps your doctors see medical conditions before anyone else, giving you information that can help save your child's life.
- Early treatment
  - Newborn screening allows babies to get needed treatment which is important to protect their health.

# Health Care Professionals

- Value of the program
  - Newborn screening saves lives by detecting problems early and getting babies to appropriate care.
  - Early detection leads to early treatment, which can make a difference in the lives of your patients.
- Value to patients
  - Talk with your patients about the importance of newborn screening.



# Recommended Next Steps: Planning

- Create a draft logic model for a strategic visual capturing resources, activities, outcomes, and goal
- Gather additional insight into audiences
- Identify baseline data to collect for evaluation

# Recommended Next Steps: Audiences

- Define specific call to action for each prioritized audience (e.g., what we want them to do)
- Refine definition of each audience for a greater level of specificity for message and outreach strategies
  - Health care professional audiences can include OB/GYN, peds, RN, NP, etc.
  - General public can be defined more narrowly with a specific call to action in mind

# Recommended Next Steps: Messaging

- Expand messaging
  - Overall value of the program
  - Each “piece” (e.g., detection, treatment, outcomes)
  - Different HCP roles
- Test messages with audiences through focus groups, interviews, or other form of qualitative research

**50<sup>th</sup>-Year NBS Campaign 2013:**  
***A joint activity of CDC and APHL***

# **2013 Campaign Audience**

## **Target Audiences**

- **Expectant parents and families**
- **Healthcare providers**
- **Policy makers**
- **State and national media**

**Final audience choice and activities will be heavily depending on available funding**

# Planned Activities

## Combined NBS Symposium APHL/ISNS

- Planned for May 5-10, 2013
- Located in Atlanta, GA
- Focus will capture the 50<sup>th</sup> Anniversary
- Site visits to GA State PHL and CDC/NSMBB
- Planning to begin in June, 2012

APHL: Association of Public Health Laboratories

ISNS: International Society for Neonatal Screening

# Planned Activities

## NBS 50Yr Celebration Exhibit

- Newborn Screening artifacts and historical memorabilia
- Customized and made transportable for a variety of relevant meetings

# Planned Activities

## **NBS Celebration Book/Interactive Media**

- **Highlighting the story of newborn screening**
- **Parent/patient perspectives**
- **Targeted to general public, legislative decision makers**
- **Production costs; funding sources & needs**
- **Dependent on campaign themes and messaging**



# **Planned Activities**

## **National NBS Commemoration Event**

- **Location: Washington DC**
- **Targeted to legislative decision makers**
- **Scope and themes of event still being defined**
- **TBD: number of people, attendee list, time of day, length of meeting, sequential activities**
- **Date: Fall 2013, Washington DC**
- **Funding , key speakers, spokespersons**

# **Other Campaign Activities**

## **Public Service Announcements**

- **Television, radio, print, internet/digital media**
- **Targeted to the general public**
- **AIM: “Raise Awareness”; deliver a “Call to Action”**
- **Creation of key messages for the campaign**
- **Identifying “State Leaders” as spokespersons**
- **Scope is highly dependent on Funding**

# Ideas & Themes Influencing Vision

\*\*\*Still a work in progress\*\*\*

- 1. NBS is a system of detection, prevention and protection**
  - Multifaceted program
  - Not just a PKU test
- 2. NBS should be considered a standard of care**
  - Represents one of many tests/evaluations performed on the newborn before he/she leaves
- 3. Program impacts newborns – and also families and communities**

# Ideas & Themes Influencing Vision

\*\*\*Still a work in progress\*\*\*

4. **Equip parents with questions they should ask a healthcare provider**
  - A public encouraged to seek out answers from HCPs will drive the need for awareness and more information
5. **Equip physicians with message cards and information to respond to patients**
6. **Program impacts newborns – and also families and communities**
4. **Data beats rhetoric**
  - Be accurate in messaging and statements

# Ideas & Themes for Messaging

\*\*\*Still a work in progress\*\*\*

**Newborn Screening is your baby's first test**

*... Get the facts from your healthcare provider*

**Over 12,000 newborns were identified in 2009 from early detection and intervention of NBS**

*... Know your baby's result*

**Newborn screening is part of routine care for your baby**

*... Expect it, become informed*

# Summary

- ❑ Awareness about newborn screening is low among virtually any audience you can think of
- ❑ Parents say they would like more information about NBS
- ❑ Some people are concerned that increasing awareness could have a counterproductive effect
- ❑ But, the benefits of increased awareness (hopefully leading to informed acceptance of NBS rather than passive or unknown acceptance) probably outweigh the potential cost
- ❑ How we go about the campaign(s) will be important
- ❑ Lots of ideas and big plans for 2013
- ❑ Evaluation of effects will be important
- ❑ The campaign is just the beginning